

# **Georgia's Neurobehavioral Crisis: Lack of Coordinated Care, Inappropriate Institutionalizations**

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*Public Policy Report and Recommendations*



**Brain and Spinal Injury Trust Fund Commission**  
State of Georgia  
October 2007

## Mission

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The Brain & Spinal Injury Trust Fund Commission enhances the lives of Georgians with traumatic brain and spinal cord injuries. Guided by the aspirations of people with traumatic injuries, the Commission supports lives of meaning, independence and inclusion. As the state's Lead Agency on Traumatic Injuries we:

- administer the Central Registry to identify those who are injured,
- distribute resources through the Trust Fund, and
- advocate for improvements in statewide services.

### Brain and Spinal Injury Trust Fund Commission

2 Peachtree Street NW, Suite 26-426

Atlanta, GA 30303

Phone: (404) 651-5112

Toll-free: (888) 233-5760

Fax: (404) 656-9886

[info-bsitf@dhr.state.ga.us](mailto:info-bsitf@dhr.state.ga.us)

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## *Public Policy Report and Recommendations*

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## Executive Summary

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**N**eurobehavioral problems related to traumatic brain injury have a significant impact on individuals, families, and society. People with neurobehavioral problems have difficulty controlling their emotions and behavior and can pose a risk to themselves or others. As a result, they require particular supports to be able to live in the community, or at least, to live in a setting where they do not pose a danger to others or themselves. However, because of a lack of sufficient funding and appropriate and effective services, people with neurobehavioral issues are ending up in costly settings such as nursing homes, prisons or state hospitals, or they are placed out of state or end up homeless. Such inappropriate placements are taking a significant toll on lives as well as the state of Georgia in terms of higher costs, lost wages, and lost contributions to local communities.

Neurobehavioral problems are problems with a person's ability to behave socially, communicate, and control emotions, and are caused by an injury to the brain such as traumatic brain injury (TBI). According to the Centers for Disease Control and Prevention (CDC), ***TBI is the leading cause of death and disability for any person age 45 or under.*** The majority of TBIs are caused by motor vehicle crashes, falls, violence, child abuse, occupational injuries, war-related injuries, and/or sports and recreational injuries. Other types of injury to the brain, called acquired brain injuries, including brain tumors, anoxia (loss of oxygen, often caused by heart failure), or strokes, can also result in neurobehavioral issues. The CDC estimates that approximately 2% of the U.S. population is living with a long-term disability relating to a traumatic brain injury. This means that approximately 187,000 Georgians are currently impacted by this disability, 10% of whom may need ongoing, intensive supports because of behavioral issues.

Providing effective services and support for people with neurobehavioral problems and their families is a complex task for state and local governments. Indeed, it is a problem that challenges most states in the country. In Georgia, the key components and services necessary to provide a coordinated system of care to address the complex and unmet needs of people with TBI are not available, largely due to a lack of public and private funding. These key components include: *screening and identification, training and awareness, rehabilitation, and long-term or life-long supports*. As a result:

- Many Georgians with neurobehavioral issues have not been properly identified and diagnosed and are thus not receiving appropriate services (pages 12-13);
- Few professionals have training in how to provide services to people with neurobehavioral issues, resulting in inappropriate treatment and increased costs of care (page 13);
- Many Georgians with neurobehavioral issues are not receiving even basic rehabilitation for their injury because of a lack of coverage for these services by Medicaid and private insurance, and are forced to live with significant impairments, higher costs of care, and increased risk of institutionalization (page 14); and
- Critical community services and supports that help people with neurobehavioral issues remain in the community or in the least-restrictive setting do not exist in Georgia (pages 15-18).

The state of Georgia has an opportunity to develop funding and services to address these problems and provide these key components, thereby creating a coordinated system of care and support for people with neurobehavioral issues. In so doing, it will reduce spending, increase productivity and quality of life for its citizens, and serve as a model for other states throughout the country.

The Brain and Spinal Injury Trust Fund Commission advocates for a coordinated system of care that supports people with a significant TBI, their family members and primary caregivers, and which offers other alternatives for individuals to live as independently as possible. The recommendations presented below were developed by a panel of experts and are the result of more than fifteen years worth of discussions, meetings, and research at the state and national level (Appendix A).

## Recommendations

The Commission strongly recommends the development of a coordinated system of care for Georgians with significant behavioral issues resulting from traumatic brain injury. Such a coordinated system would significantly improve the quality of life for people with brain injury, reduce the use of state funds for inappropriate and ineffective services, and create a model of care for the rest of the country. To accomplish this, the Commission recommends the following:

**Recommendation 1:** Create a legislative study committee to review this report and its recommendations, and to identify legislation, funding, responsible entities, and other infrastructure to create and support a coordinated system of care for Georgians with significant traumatic brain injuries.

**Recommendation 2:** Develop a coordinated system of care that addresses the following four key components:

### **I. Screening and identification**

- Expand capacity for behavior screening, assessment and evaluation for children and adults to identify people with significant behavioral issues resulting from brain injury.

### **II. Training and awareness**

- Develop and provide training for direct care staff, providers, paraprofessionals, educators and other professionals to increase awareness and expertise in behavior associated with brain injury.
- Develop and maintain a centralized database of direct support staff, providers, paraprofessionals, educators and other professionals who have expertise in behavior associated with brain injury.

### **III. Rehabilitation**

- Expand funding sources and opportunities for post-acute rehabilitation, community and school re-entry services.

### **IV. Long-term or life-long supports**

- Expand capacity for service coordination and case management services.
- Expand capacity for short-term, long-term and intermittent support such as professionally-designed behavioral supports, counseling, community-based and in-home care, personal care/support, and crisis management services.
- Expand capacity for support services and respite options for caregivers.
- Develop capacity to provide for structured, community-based residential treatment and care for individuals who are a danger to themselves and others.

**Recommendation 3:** Provide oversight and the development of policies to support a coordinated system of care facilitated through the Brain & Spinal Injury Trust Fund Commission, the Lead Agency on Traumatic Brain & Spinal Injuries for the state of Georgia.

The Commission presents the following report to explain further the need for support for people with neurobehavioral issues and its recommendations for a coordinated system of care. Currently, no state has developed a comprehensive, coordinated system of support for people with significant behavioral issues resulting from TBI, however, some states have successfully developed initiatives that can be replicated and combined to form such a system. Included in the report are examples of some of these models.

## Prologue

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### **B.'s Story: A Life Disrupted by an Inadequate System**

After B., a father in his 20's, was injured in a car crash in October, 2004 he was admitted to a regional medical center in Georgia for treatment for a severe TBI. As the result of his TBI, B. developed significant behavioral issues. The hospital tried to discharge B. to a neurobehavioral treatment program in order to address his behavioral issues, however, no funding was available to pay for a program that provides 24-hour behavioral, cognitive, and physical treatment in a community setting. Without such treatment his family was unable to manage him. As a last resort, the hospital attempted to admit B. to a nursing home, but **117 nursing homes denied him admission to their facility because they weren't equipped to care for someone with significant behavioral problems.**

B. was stuck. The regional medical center had no choice but to keep him in their facility. For 14 months the hospital cared for B. at their expense, a total of \$552,500.

The hospital staff was not trained to care for a person with neurobehavioral issues either. For example, when the hospital staff approached B. to bathe, dress, or treat him he would become frightened and become verbally or physically abusive. In response the staff would call in additional employees to hold B. down for care or treatment, which only increased his fear and escalated his behaviors. As a result, B. did not always get the basic treatment that he needed such as physical therapies and grooming. Because of this his arms and legs became severely contracted, requiring numerous surgeries for tendon releases and resulting in a great deal of physical pain for B. This too intensified his behavioral problems.

Finally, after 14 months a specialized brain injury rehabilitation hospital in Atlanta admitted B. with an agreement that the regional medical center would assist in finding the next placement for B.

By then, B. was in severe pain and could not sit up by himself. Severe contractures had reduced the use of his legs. Four people were needed to help him with daily living activities, including bathing and dressing, because he had developed such an aversion to people helping him with his care following his experience at the medical center. Indeed, most of his outbursts occurred when

continence garments were changed, or when he was assisted to use the toilet, transfer in and out of a wheelchair, or other physical activity. Once an outburst began, B. could not be redirected and the only way to diffuse his behavior was to remove him from the room or situation.

Despite this, appropriate treatment from trained professionals soon bore fruit: in time, B. needed only two people to change or transfer him, and he was able to sit in his wheelchair for long periods of time without fatigue or pain. His outbursts became less frequent, and when he did have an outburst, he would apologize, even though he was not always aware that he had reacted aggressively. After 70 days, B. was ready to be discharged for neurobehavioral rehabilitation. But to where?

Finding such a program in Georgia proved difficult since the only neurobehavioral program in the state could not accept him because of his physical limitations, lack of places to go upon discharge, and lack of funding. To address the funding issues, the Atlanta rehab hospital helped B.'s parents to apply for funding under the Independent Care Waiver Program (ICWP), however, **ICWP denied B. because the costs of a rehabilitation program for him would exceed the allowable amount for ICWP and because ICWP believed that B.'s behaviors could not be managed in the community.** His parents filed an appeal through the Georgia Advocacy Office. But B. still had nowhere to go.

Ultimately, the regional medical center, where he was first treated, agreed to pay for 3 months of neurobehavioral rehabilitation in an out-of-state program, rather than readmit him.

The out-of-state program accepted him but, once again, due to few discharge options, B. ended up spending 11 months there at a total cost of \$198,000.

By the end of his stay B. needed only one person to dress him. In fact, B. reached a point where he was able to assist with his dressing and transferring in and out of bed. These small gains resulted in monumental

changes: his quality of life increased and his costs of care decreased. While he still expressed verbal aggression, his outbursts were much less frequent and no longer included physical violence. B.'s behavior improved so much that he was soon able to have visits with his son. Seeing this, B.'s parents, who are in their 60's, were thrilled and encouraged. They felt up to the task of caring for him in their home if they had sufficient financial support for personal and behavioral care.

However, ICWP continued to deny B. funding for his care in the community, saying that he posed too great a threat to himself and others because of his aggressive behavior, and that the costs of his care would exceed their approved limit. During an appeal hearing, his parents presented video evidence of his improved behavior, including his visits with his son. As a result, ICWP agreed to provide funding for B., who moved into his parents' home in January 2007—27 months after his accident. But B.'s story does not end here.

***Unfortunately, there were insufficient services in the community to support a person with neurobehavioral issues.*** Although ICWP provided funding for attendant care, available attendants did not have specialized training in neurobehavioral issues. They were unable to manage and redirect his behavior. The entire burden for his care, both physical and behavioral, was left to his aging parents, who quickly became overwhelmed and fatigued. They felt they had no choice but to place B. in a local nursing home, even though they wanted B. to be able to live with them. As a result, the ICWP discontinued funding for B.'s care.

As of the writing of this report B. has been suddenly and prematurely discharged from the nursing home and

placed back at the regional medical center where he was first admitted. It is unclear why the nursing home discharged him. The nursing home staff had received training in managing neurobehavioral issues and reported that, as a result, it had become easy for them to manage B.'s behavior. There is some concern that the reason for discharge was the nursing home administrators' reluctance to keep B. in their facility. Attorneys for the regional medical center are now suing the nursing home. It is important to note that since returning to the regional medical center, where he originally had significant behavioral problems, B. has had no behavioral problems. B.'s parents have reapplied for the ICWP and are exploring alternatives for his care, but at this point they have almost no options left.

***Where did we go so wrong?*** Consider this: Sufficient funding and services for neurobehavioral rehabilitation and community supports would have:

- Prevented B. from developing severe behavioral problems; requiring significant and costly rehabilitation.
- Prevented B. from developing severe contractures in his limbs, which caused great pain and required several costly surgeries to correct.
- Prevented B. from having to be sent out of state for neurobehavioral treatment.
- Enabled B. to return home in months, rather than years.
- Saved the regional medical center hundreds of thousands of dollars in costs of care and staff time.
- Allowed B. to live in the community with his family and help raise his son.

## Overview

### *The Cause and Nature of Neurobehavioral Issues*

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#### **What is a Traumatic Brain Injury (TBI)?**

A traumatic brain injury (TBI) is caused by a jolt, blow or penetrating injury to the brain. Georgia defines traumatic brain injury as “an injury to the brain, not of a degenerative or congenital nature, but arising from blunt or penetrating trauma from acceleration-deceleration forces, that is associated with any of these symptoms or signs attributed to the injury:

- decreased level of consciousness
- amnesia
- other neurological or neuropsychological abnormalities
- skull fracture or
- diagnosed intracranial lesions.

These impairments may be either temporary or permanent and can result in a partial or total functional disability.”

#### **How many people have TBI?**

Traumatic brain injury is the leading cause of death and disability for anyone age 45 or younger. According to the Centers for Disease Control and Prevention (CDC) there are 1.5 million new TBI's every year in the United States. In Georgia, the state's Central Registry for Traumatic Brain & Spinal Injuries reported that over 42,000 Georgians with TBIs were treated and released from emergency departments in 2005 and an additional 6,320 sustained TBIs that were severe enough to require admission to the hospital.

The CDC estimates that approximately 2% of the U.S. population, or at least 5.3 million Americans, currently have a long-term or life-long need for help to perform activities of daily living as the result of a traumatic brain injury. Accordingly, this could mean that approximately 187,000 Georgians have a long-term or lifelong disability relating to a traumatic brain injury. Of these, studies estimate that between 3 and 10%, or anywhere from 5,600-18,700, of them will require ongoing, intensive services and supports due to the behavioral issues they present to their families and communities.

It should be noted that, in addition to TBI, approximately 15,000 Georgians sustain brain injuries each year that are the result of other causes, such as strokes, tumors, birth defects, etc. These brain injuries are referred to as acquired brain injury (ABI). Many people with ABI experience neurobehavioral issues too and require the same kinds of supports as people who develop behavioral issues from TBI. The location of the damage, rather than the cause of the damage, determines whether a person may develop behavioral problems. The services and supports that are described in this report are necessary to assist a large number of people who have sustained either an acquired or traumatic brain injury.

#### **What are the causes of TBI?**

The primary causes of TBI are motor vehicle crashes and falls. Other causes are gunshot wounds, violence and assaults, industrial or work-related injuries, and sports-related injuries. TBI can happen to anyone of any age. Falls are the leading cause of traumatic brain injury for children ages 0 to 4 years. This age group has the highest rate of TBI-related emergency department visits, followed by older adolescents ages 15-19 years. Other causes of TBI for children and youth include bicycles, skate boards, other sporting injuries and child abuse.

In addition, the Defense and Veterans Brain Injury Center has declared that TBI is the “signature wound” of the war in Iraq. This is because a significant number of soldiers are returning from Iraq with brain injuries that were caused, in part, by explosive devices resulting in concussive shock blasts or “blast injuries” that are damaging to the brain.



## What are the costs of care for people with TBI?

Whether the injury is the result of a car crash, a slip and fall, assault, or sports activity, the economic consequences of TBI can be enormous. In the United States, the average lifetime cost of care for a person with a brain injury ranges from \$600,000 to \$1,875,000, although studies have shown that the lifetime costs of care for someone with a severe TBI can reach as high as \$4,000,000. This does not include lost earnings of the injured person or family caregivers. The total cost of TBI to the nation is estimated at \$56.3 billion annually. Research has shown, however, that these costs can be reduced with appropriate and effective services and supports, as described in this report. (For more information about TBI, see Appendix D.)

## What are neurobehavioral problems associated with brain injury?

According to the Brain Injury Association of America, the term neurobehavior refers to “an individual’s ability to process thoughts or to think, behave socially, communicate, and control emotions.” Thus, the term neurobehavioral is frequently used to describe the significant behavioral problems that often result from an injury to the brain, such as a traumatic brain injury. These cognitive and behavioral problems may relate to:

- concentration
- memory and attention
- impulsivity
- aggression
- irritability
- depression
- moodiness
- changes in personality

In laymen’s terms, a person with neurobehavioral issues may be verbally disruptive or threatening, destroy property, behave inappropriately sexually, resist assistance from others, or exhibit physical aggression. These cognitive and behavioral issues have the most significant impact in terms of an individual’s ability to return to work and reside in the home and community. This is not surprising when considering that a brain injury often involves significant injury to the frontal lobes, which means that the person can no longer regulate behavior as well as prior to the injury. They may say things that are inappropriate or hurtful, making it difficult to maintain employment or relationships. Or, they may act out in such a manner that it is potentially harmful to themselves and others. In some cases, people with neurobehavioral issues have jumped through windows, assaulted their loved ones, tried to gouge out their own eyes, and sexually molested others. These acts were committed by people who, prior to their injury, had no previous history of self-injury, violence, or sexually-deviant behavior.

It is extremely important that caregivers, families, support staff, and agencies that provide services and supports understand the nature of behavioral issues following TBI. For example, people who are extremely confused and agitated do not shout at and act aggressively against other people “on purpose.” They do not tip over furniture on a rehabilitation unit simply because they are unhappy about being there. In many situations, the behavioral issues presented by a person who has experienced a brain injury are no more controllable (or amenable to verbal instructions) than another individual’s ability to walk (e.g., imagine instructing an individual who uses a wheelchair to “get up and walk”). Recognizing these facts can have a remarkable impact on our approaches to treatment and our interactions with individuals who have experienced TBI.

In addition to the direct behavioral effects from TBI listed above research also indicates that people with TBI are at higher risk for experiencing psychiatric disorders in the months and years following the TBI. In general, recent studies have shown that 20 – 50% of people with TBI may have at least one psychiatric disorder in the first year following injury, resulting in increases in re-hospitalizations and lengths of stay in subsequent years. Specifically, psychiatric disorders that have been most frequently associated with brain injury include depression, alcohol abuse, panic or anxiety disorders, phobias, and other types of disorders.

In preparing its recommendations, the Commission has made distinctions between two levels of neurobehavioral impairment: 1) behaviors that may impede an individual’s ability to return to work or school, maintain relationships and resume community living, and 2) more severe behaviors that may result in a threat to the safety of the individual and/or others. This differentiation is necessary to plan for the type of services to accommodate these challenging, unique behaviors.

## **How do neurobehavioral issues affect children?**

Children who sustain a brain injury are three times more likely to develop behavioral and emotional problems even if the child had no prior history of difficult behaviors. However, for children who receive a brain injury at an early age, neurobehavioral problems may not become apparent or identified until many years after their injury. Often, by the time difficult behavior becomes apparent, children are many years post-injury and the diagnosis of TBI is not available in their current medical or school records. This is because a child does not develop the capacity for higher reasoning until adolescence so any behavioral or cognitive problems may not manifest until that time. As a result, many children with TBI are often diagnosed or classified as having a learning disability, an emotional disability or mental retardation rather than neurobehavioral issues following a TBI. This can cause significant stress and exacerbate symptoms for the child, the family, and the school system when a child is improperly diagnosed (see pages 28-30).

## **What is the impact of neurobehavioral issues on families and loved ones?**

Brain injury is devastating not only to the people who sustain the injuries but also to their family members and loved ones. This is particularly true when the person exhibits significant behavioral changes and problems following a brain injury. Suddenly, family members must try to make sense of a mother who was so patient and involved with her children prior to the injury, but who is now easily angered and prefers to spend most of her time alone, or a son who was once an honor student with plans for college prior to the injury, but who now is getting arrested for selling drugs. This makes brain injury complicated and confusing for family members who are, on one level, thankful that their loved one survived the injury but on another level grieving the loss of their loved one's former personality and trying to understand who this new person is.

Family members and loved ones of people with neurobehavioral issues experience an incredible amount of stress, not just because of the emotional impact but also because of the financial and other practical issues that come with caring for a person with brain injury. Family members are forced to navigate a service system that is complex and fragmented in an effort to find appropriate and effective services for their loved one. This process can be frustrating and extremely time-consuming, particularly as they find that the services that they need do not exist or are not affordable. Because of this lack of services the burden of care is often left to the family members who are forced to give up their jobs and other pursuits in order to care for their loved one. However, because caring for someone with severe neurobehavioral issues can be extremely difficult, all-consuming, and sometimes risky family members often get burned out, develop serious emotional or physical problems, and give up caring for their loved one altogether.

## **How are neurobehavioral issues caused by brain injury different from other cognitive disabilities?**

When talking about significant behavioral issues caused by TBI it is important to distinguish them from other cognitive behavioral disabilities such as mental illness or developmental disabilities because the problems, needs, and support strategies are very different. This is not to say that some individuals with brain injury cannot be meaningfully supported in programs that have been designed primarily for persons with other disabilities. Instead, it means that the need for specialized services for people with TBI does exist and that many programs designed to serve persons with mental illness or developmental disabilities are simply not prepared to provide this specialization.

This is best illustrated by the following comparison:

- An attorney in his 40's sustains a TBI in a car accident. Suddenly, he is unable to remember whether he showered, how to write a check, or even how to prepare a meal. He remembers that prior to the accident he was a successful attorney and coach of his son's soccer team, and he struggles to understand why he can't practice law again and why he suddenly screams at his children and prefers to remain alone in his bedroom. Because of the TBI he has lost the ability to cope with these tremendous losses, causing him to lash out at others and need reminders from his children to turn off the oven.

- A man in his 40's has lived his entire life with a developmental disability from birth. Because of his intellectual/cognitive limitations he has not been able to develop higher cognitive skills or function completely independently as an adult. His parents and educators have taught him to take the bus to a sheltered job and to keep his room and clothes clean. His parents keep track of his finances and paid caregivers make sure he gets to work each day. He becomes frustrated when there are changes to his routine or his caregivers and sometimes hits himself or refuses to go to work.

While it would appear that these two men, who both have cognitive behavioral problems, have similar issues requiring similar supports, this is not the case. The man with TBI needs help to understand the injury's effects and the ways in which his life is different post-injury. He also needs help to create and maintain an environment that supports his strengths and enables him to manage his own behaviors. The man with the developmental disability, however, needs support and interventions that are focused on shaping appropriate behaviors for the first time, establishing consequences to maintain those behaviors, and simplifying his environment for a life-time. Most care providers and society in general are most familiar with this type of behavioral scenario and often try to fit someone with a brain injury into this style of support, which is ineffective and often harmful for the person with brain injury.

The behavioral strategies used to support people with TBI can differ markedly from those used to assist people with mental illness and developmental disabilities. Unlike programs for people with mental illness or developmental disabilities, programs for people with TBI must incorporate interactional, visual, and environmental components that build on the person's existing neurological strengths. In addition, the design of behavioral strategies for people with TBI may, in many cases, include the person in the program's design much more fully than approaches that have been designed for other populations. The successful approach will respect the person's pre-injury identity (occupation, role in family, etc) and will rebuild insight into current strengths and limitations that were destroyed by damage to the front area of the brain. In general, rather than trying to employ behavior strategies to "shape" behavior that has not existed previously, the focus of approaches in TBI should be on structuring the environment to help the individual utilize past strengths and current abilities to compensate for cognitive challenges and learn to effectively manage his or her own behavior.

## **A Coordinated System of Care**

### *Four Key Components*

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#### **What is needed to help individuals with TBI who have significant behavior problems?**

It is possible to provide sufficient support to a person with neurobehavioral issues to live in the community, or to live in the least-restrictive and most appropriate community-based setting possible. To do this it is necessary to address four key components that, when combined, can guide the development of a comprehensive and cohesive system of care for people with TBI. The following section describes these key components and, where available, examines models that other states have employed to implement these components:

- **Screening and identification**

Proper screening for people with TBI is critical in order to identify any neurobehavioral issues as soon as possible following the injury and then arrange and provide appropriate supports. As such, screening is an effective prevention tool as it may prevent people with neurobehavioral issues from being misdiagnosed, receiving inappropriate services and/or medication, receiving no treatment at all, or being arrested, imprisoned, placed in a state mental hospital, or homeless.

Screening helps determine whether a person may be at risk of experiencing neurobehavioral issues as the result of a TBI. Screening can be particularly useful for people who may not think that they have residual effects from a TBI or who may not even remember having sustained a TBI. There are a variety of examples of screening tools that are available for use throughout the country; most notable is the Brain Injury Screening Questionnaire (BISQ) developed by Mount Sinai Hospital in New York.

Once a person has been screened for possible neurobehavioral issues it is critical to have formal identification and confirmation of their behavioral problems. This is generally accomplished by a neuropsychological evaluation, where standardized tests are used to evaluate different aspects of functioning, including attention, motor performance, perceptual coding, learning, memory and affect. Observing how a person functions in “real-life” situations is also critical in order to assess functioning skills, behavior and mood. Individuals with TBI often lack insight or self-awareness and may be unable to accurately report how they perform in day to day situations. Through this evaluation process, which may also include a functional behavior analysis and sometimes involve a team of other therapists, identification of specific neurobehavioral issues and contributing cognitive impairments is completed and a plan is developed for managing risks and addressing the problems.

Because people with TBI access services from a variety of agencies it is critical that screening and identification be implemented across systems and in a variety of settings, including hospitals, mental health agencies, developmental disabilities programs, schools, prisons, homeless shelters, etc. This requires training of personnel and coordination among agencies. A number of states, including Alabama, New Hampshire, and New York, have developed successful models for cross-training and collaboration among a variety of agencies.

One of the cost-effective ways in which states have accomplished this is through the use of mobile resource and consultation teams. The state of New Hampshire has developed such teams at the state and local level that provide training, consultation, and crisis management assistance to families, educators, direct care workers, and other professionals who are working with people with neurobehavioral issues. These teams consist of a neuropsychiatrist, pediatric psychiatrist, neuropsychologist, behavioral psychologist, case managers, and individuals knowledgeable about state and local resources. The teams are equipped to assist a variety of agencies and personnel with screening and identification of people with neurobehavioral issues.

Presently, the state of Georgia does not have a systematic way of screening and identifying people with neurobehavioral issues. Screening efforts are primarily limited to service providers with expertise in TBI, such as the rehabilitation hospitals, Side-by-Side Brain Injury Clubhouse, Restore Neurobehavioral Center, etc., however, this assumes that a person with TBI has already been identified and referred to such experts. Generally, screening efforts are fragmented or nonexistent among other agencies and providers whose populations are more diverse, but who may include people with TBI. In these cases, the professionals who are conducting the screenings usually do not have training and expertise to identify and understand the complex needs of people with neurobehavioral issues. An example of this is the Independent Care Waiver Program (ICWP), which conducts screening during its application process but often fails to identify the range of needs for community support for people with neurobehavioral issues and thus denies admission to the Program.

- **Training and awareness**

As previously stated, it can be challenging to provide support for people with neurobehavioral issues. This is particularly true for the people who are actually providing the support: rehabilitation professionals, family members, other caregivers, personal attendants, teachers, nurses, therapists, etc. Specialized training for care providers is critical and should be conducted in a variety of settings and across agencies in order to:

- increase awareness about neurobehavioral issues and the specialized services that are required to support a person with TBI appropriately and effectively;
- conduct appropriate screening and evaluation, helping to recognize the signs and symptoms of neurobehavioral problems and to know how to identify a person with such issues;
- provide adequate and appropriate rehabilitation and help ensure that it is not inappropriately interrupted;
- provide adequate and appropriate support services, ensuring that caregivers and staff have interest and expertise in working with individuals with traumatic brain injury and are equipped to identify and deescalate potentially dangerous behaviors when they arise, rather than responding in a way that is likely to escalate inappropriate or negative behaviors, or that is abusive;
- reduce stress, high turnover, and burnout in families, caregivers and staff by providing sufficient tools to manage uncontrolled behavioral outbursts, unpredictable anger, physical aggression and the stress that these situations place on the families and others; and
- reduce long-term costs of care, inappropriate placements.

Currently, Georgia has no organized training programs for direct care staff, families, other caregivers, or other professionals. One reason for this may be that the process of developing and delivering appropriate training to the agencies, families and support staff who need it is not a simple task. Agencies and staff may not recognize the need for such training and are often challenged by other demands for their time. Nevertheless, there are a number of ways in which training can be developed and incorporated across systems. Collaborating with colleges, universities, and vocational schools ensures that training on TBI is incorporated into curricula in a variety of disciplines. It is also possible to develop training for professionals, including in-service trainings, and partner with agencies to ensure the inclusion of such trainings for their staff. This approach has proven to be successful in Massachusetts. In addition, the state of Missouri has developed core competencies for direct support staff to ensure that they are educated in the appropriate ways to provide care for people with neurobehavioral issues.

To ensure that family members and caregivers have access to professionals who have received specialized training in neurobehavioral issues it is also important to have a centralized database available through a helpline. Such a database could be used to maintain information on service providers and agencies that are equipped to serve people with neurobehavioral issues and can serve as a critical tool for service coordination (see page 15). Currently, no such database or helpline exists in Georgia.

- **Rehabilitation**

Once a person with brain injury has been identified as having neurobehavioral issues it is critical that he/she receives adequate and appropriate rehabilitation to increase his/her ability to live successfully in the community or in the least-restrictive setting possible. Obviously, rehabilitation is most effective if provided soon after the injury, however, it is vital and can still be effective for people who may be identified with neurobehavioral issues long after their injury occurred. Appropriate therapy for neurobehavioral issues may include: a) cognitive and behavior therapy, as well as counseling and psychotherapy; b) transition services, including organizing and/or arranging the home environment in such a way that functional skills are developed or facilitated; and c) pharmacological interventions.

- Cognitive and behavior therapies are often provided soon after a person is medically stable. The rehabilitation focuses on restoring speech and language, mobility, cognitive, social and behavior skills and/or learning compensatory strategies to help with specific deficits. Emphasis is placed on addressing the problems that are most likely to impact the person's ability to live as independently as possible after he or she leaves the rehabilitation setting. In the case of neurobehavioral issues, work needs to be directed toward development of strategies to help an individual self-manage his or her emotions and behavior, using compensatory strategies similar to those used to address memory issues or other routine tasks. Counseling and psychotherapy may also be used to treat depression and loss of self-esteem associated with neurobehavioral problems.
- Transition and follow up services with the individual in his or her home setting following rehabilitation is of the utmost importance. Individuals with traumatic brain injury generally have trouble with transferring learned behavior from one setting to another setting. When people with brain injury change their environment, such as leaving a rehabilitation facility to home, they will often need help with structuring their new environment in such a way that it supports what they have learned. It is important, therefore, to teach functional skills in context and in an established routine, repetitively.
- When used in conjunction with cognitive and behavioral therapy psychopharmacology can be effective in treating aggression, irritability, depression and anxiety. Where available, a neuropsychiatrist or a physiatrist with expertise in the evaluation and treatment of neuropsychiatric disorders following a traumatic brain injury may be needed in treating these symptoms. Counseling is also beneficial to help people with TBI and their family members address the problems and disorders that may follow brain injury, however, specialized counseling for TBI may be difficult to access, either because of geographic location or a lack of professionals with such training. To address this, the state of Missouri developed the use of telerehabilitation to bridge the gap between the rehabilitation hospitals and the community, and to increase access to specialized psychological services in the community. As a result, many community mental health providers, social workers, psychologists and counselors in rural areas have been recruited and trained to provide services via telerehabilitation technology.

While it would seem that rehabilitation is a basic need for anyone who has been injured and is essential to improve functioning, quality of life, and the ability to live in the community, many people are unable to receive sufficient rehabilitation because of a lack of coverage for these services both by Medicaid and private insurance companies. This is true in Georgia where private providers who offer rehabilitative services for people with brain injury are limited to providing only basic services to people with Medicaid or private insurance, or otherwise serving only people with workers' compensation, injury settlements, or private funds because of limits placed on rehabilitation by Medicaid and private insurers. Many states have worked diligently to educate Medicaid and private insurance companies about TBI and neurobehavioral issues in order to expand the types of covered services for care and rehabilitation of TBI. To ensure adequate funding for services for children with TBI some states have also worked with their state's Office of Children's Medical Services to develop funding and supports.



- **Long-term or life-long supports**

As previously stated, it is possible for many people with neurobehavioral issues to live successfully in the community. To ensure their long-term success people with neurobehavioral issues and their family members need to have access to a range of services to support them in living in the community. These services can include: a) service coordination; b) community supports, such as professionally-designed behavioral supports, counseling, community-based and in-home care, personal care/support, and crisis management services; c) support and respite for caregivers; and d) options for structured community-based residential programs. Clearly, people will require varying degrees of support from others to remain free from potential harm, accomplish their personal goals, and attain a high quality of life.

- Service coordination is absolutely essential to providing a seamless system of care. Families are overwhelmed by their grief, loss of financial security, lack of knowledge of the needs of their loved one, and lack of familiarity with the services and funding available to address those needs. The world as they know it has changed dramatically overnight. At the same time, there is no system to support communication and coordination among hospitals, rehabilitation programs, education and other state and local programs in order to expedite services and supports. There is no “one-stop shop” for families who need support and services for brain injury. Service coordinators help with assessing and identifying an individual’s needs, facilitating the provision of services and supports, monitoring and overseeing the quality of services provided, and conducting public education and outreach. They work closely with other state and local systems and resources in order to streamline the process of obtaining multiple services from multiple agencies and to avoid potential duplication of or conflicts in services.

In developing this report it has become clear that Georgia needs to have a system of service coordination since the state currently lacks a point of contact for people to call to get immediate assistance or navigate the system of services. States who have begun to develop a coordinated system of care for people with neurobehavioral issues have found it beneficial to begin with the development of service coordination services, as this helps to identify the range of needs and gaps in services for people with neurobehavioral issues. One service that can facilitate service coordination in Georgia is the Central Registry for Traumatic Brain & Spinal Injuries, which collects names of people with TBI who were treated in a hospital setting and provides information on available services. It is possible that the Registry could be used to make referrals for service coordination.

While service coordination can play a critical role in ensuring that a person with TBI receives the services that he or she needs there is little funding available to pay for this much-needed service and to ensure that people who provide service coordination have sufficient training in the support of people with neurobehavioral issues. Once again it is critical that Medicaid and private insurance companies understand the need for this service and expand coverage to including funding for it. As with previously-discussed services, a number of states have worked with their Medicaid offices to provide funding for administrative and/or targeted case management services through the waiver program, while others have included this service in their TBI trust fund (such as the Brain & Spinal Injury Trust Fund in Georgia). While this strategy has been effective for adults with neurobehavioral issues, several states have worked with their state Office for Children with Special Health Care Needs to develop similar arrangements for children with TBI. Both Alabama and Arizona have developed effective programs that provide service coordination for children, and which collaborate heavily with hospitals and school nurses to ensure a continuum of care.

- In order to live successfully in the community people with neurobehavioral issues need a range of community services and supports, including professionally-designed behavioral supports, counseling, community-based and in-home care, personal care/support, and crisis management services. These services are designed to treat behaviors in the home and

community setting and reduce the likelihood of people being placed in more costly settings. Unfortunately, most people with neurobehavioral issues do not have access to such services because these services do not exist in their area, providers do not have staff that is trained to manage neurobehavioral issues, or funding is not available to cover the services. Indeed, one of the most glaring gaps in Georgia's service delivery system is the lack of community supports for people with neurobehavioral issues after TBI. Medicaid and private insurance companies do not understand the need for these services and do not include these services in their coverage.

This is particularly true for crisis management services. While appropriate therapy and supports go a long way in helping people with brain injury to live in the community on a long-term basis, periodically it might be expected that there will be times when a person's behavior becomes too difficult to manage or too threatening to themselves or others. At these times, families need assistance from trained professionals to deescalate the situation or, if necessary, to provide a temporary, more secure environment until the risks associated with the person's behavior can be controlled. However, again, the lack of funding means that most people do not have access to these services. While there are many agencies that provide in-home support for people with cognitive disabilities the majority of these agencies do not provide staff that is trained in neurobehavioral issues because of the low rate of payment by the Medicaid Independent Care Waiver Program (ICWP) in Georgia (see page 24-28).

States that have worked to educate their Medicaid offices and private insurance companies have, in many cases, been able to increase the rate of pay for behavior management services in order to attract and keep the kinds of specialized services that are critical for people with TBI. In addition, twenty-two states have found it especially useful to develop a Medicaid Home and Community Based Services (HCBS) Waiver that is specific to TBI to ensure adequate coverage of behavioral interventions and crisis management services.

## **How a Lack of Supports Can Prevent Someone from Staying in the Community**

L. sustained a severe TBI nearly 20 years ago. Five years ago he began to use a computer to speak and a power wheelchair to ambulate. He receives his medicines and liquids through a feeding tube and requires the care of a nurse 24 hours a day. His family describes L. as a brilliant, college-educated man who is compassionate and considerate and who has many ideas and dreams for his future. They have worked very hard to support him in the community.

However, because of his brain injury L. often kicks, curses, insults, spits, and throws himself out of his chair, injuring himself and others. As a result, he has driven away too many care providers who were not trained in assisting people with neurobehavioral issues, and he has also been exploited by others (several times, he has given the PIN to his bank account and been robbed of all of his support funds).

While L. has a committed family and adequate financial resources, the family is exhausted and has had little recourse but to consider institutionalization because of his aggressive behavior towards caregivers. They have asked for assistance in finding a nursing home for him, however, nursing homes will not accept him because of his behavior. His family is left with no options for a loved one who needs significant, specialized support.

H. is a 21 year old male who was injured at the age of five. He cannot walk and lives at home. Increasingly, his behavior is becoming more violent, for which his family has taken him to the local emergency room. The attending doctor was told that a state mental health receiving facility will not accept a patient with a diagnosis of TBI. Thus, his family is struggling to find a program or resources to help manage his behavior so that they can keep him in the community.



Other states have made use of the mobile resource and consultation teams, discussed above, which can play a critical role in supporting families in such difficult times. The New York Medicaid program found that by providing regional resource teams that offer an array of behavioral treatment and interventions, the state saved money by supporting individuals in the community through its waiver program rather than placing them in long-term care facilities in-state or out-of-state. The state of New York has also developed a successful crisis management program for people with neurobehavioral issues that is supported by the state's HCBS-TBI waiver.

- A critical component to supporting people with neurobehavioral issues is sufficient support for their caregiver. While the majority of people with neurobehavioral issues can, with sufficient services and funding, be supported to live in the community, it is important to note that the burden of this care is held by the family members and caregivers. Understandably, the role of caregiver to a person with significant behavioral issues can be very challenging and this is particularly true when the caregiver is also balancing the need to work and care for other family members as well. Establishing a coordinated system of care for people with brain injury, as described here, can go a long way in ensuring adequate support for caregivers but it is important that such a system address the unique challenges of people who are caring for a person with neurobehavioral issues. As the website *Medical News Today* recently wrote, "in spite of growing evidence of family/caregiver distress after injury, developing appropriate intervention strategies to help families and caregivers has lagged behind."

One state that has created an effective model of support for caregivers is California. As the result of state legislation, the California Department of Mental Health contracts with eleven nonprofit Caregiver Resource Centers that serve and support families and caregivers of persons with adult-onset brain impairments, including traumatic brain injury. Services are designed to deter institutionalization, allow caregivers to maintain a normal routine, and promote quality care. The department also contracts with a Statewide Resources Consultant (SRC) that serves as the centralized information and technical assistance provider. Services provided to family and caregivers include respite, short-term counseling, support groups and education. A second goal of the program is to enhance the capacity of individuals with traumatic brain injury and family caregivers to self-manage significant behavior challenges.

- Certainly, in developing a system of care for people with neurobehavioral issues emphasis should be placed on providing services that allow people with TBI to live in the community. However, there are people who will require more structured residential treatment and care for their life-time. This is particularly true for individuals who sustain a severe TBI and whose behaviors pose a significant and ongoing threat to themselves and others. For these people it is necessary to have residential settings in which the staff is trained to provide support for people with neurobehavioral issues. Rather than nursing homes and other institutions, people with significant behavioral issues resulting from TBI should be supported in specialized community-based neurobehavioral programs that combine cognitive, behavioral, and pharmacological treatments. These programs should have the capacity to serve people on a long-term basis but should also have crisis beds available to allow someone to be removed from a home or other setting in an emergency situation, as has been done in both Minnesota and Wisconsin.

In Georgia there is only one option for specialized long-term residential treatment and long-term supported living for people with neurobehavioral issues, a for-profit program called Restore Neurobehavioral Center. Unfortunately, most Georgians with neurobehavioral issues are unable to benefit from their services because Medicaid and ICWP will not provide adequate reimbursement for their services. While Restore's published rate (the actual cost of providing care) is around \$1200/day, it has been willing to contract for discounted services of \$750/day for managed care providers, yet ICWP is only willing to pay an average of \$380

per day. This rate only covers certain services such as personal support, counseling, and behavior management and excludes room and board. Ironically, the state pays an average of \$500/day just to “house” people in the forensic unit of Central State. Over the years, Restore has received several requests to treat people with serious neurobehavioral issues who were being housed in this forensic unit. While Restore agreed to accept the matching rate of \$500/day to provide treatment for these people ICWP declined to accept this rate, thus denying people with TBI the opportunity to be released from Central State and receive specialized, community-based rehabilitation for their behaviors.

Another problem is that Medicaid and ICWP are generally willing to cover only 90 – 120 days of treatment for Restore. It is possible to have good outcomes and see improvements in behavior in 90 – 120 days of treatment as long as a person receives treatment soon after their injury and before problem behaviors become entrenched. However, people who are receiving ICWP and who are referred to Restore for treatment are generally several years post-injury and have developed significant behavioral problems that are well-ingrained. For these people, time is needed first to “undo” the unwanted behaviors before instilling newer, more appropriate behaviors. To do this well requires at least 120 – 150 days of treatment.

Lastly, ICWP will often deny funding for a program like Restore because it considers Restore to be an institution rather than a community-based resource. This is very problematic for many people with severe neurobehavioral issues since the only way that they can safely live in the community is if they have access to neurobehavioral rehabilitation programs that can provide a foundation for long-term behavioral management in the community. Ironically, ICWP’s unwillingness to provide funding for Restore generally means that a person with neurobehavioral issues will end up being placed in an institutional setting such as a nursing home.

As previously stated, Restore is Georgia’s only option for specialized long-term residential treatment and long-term supported living for people with neurobehavioral issues. In addition to raising Medicaid reimbursement rates to enable people to receive treatment from this program the state needs to develop additional long-term residential programs to meet the needs of all Georgians with neurobehavioral issues who require more intensive supports.

Massachusetts and Minnesota have developed excellent models of residential programs for people with neurobehavioral issues. The Massachusetts program is a secure program with capacity for voluntary admissions or commitments. The program was initially funded with state dollars, although it was designed with the ability to serve individuals with third-party pay, including Medicaid. Minnesota developed a 15-bed specialty unit in 1993. In developing their residential programs, both states learned very quickly that without other services, the behavioral unit became the only place where people were placed, which then quickly filled, creating a long waiting list for the program. Thus, both states developed a continuum of neurobehavioral services that includes community living programs and in-home family assistance programs. Massachusetts also contracts with a neuropsychologist who provides assessments and evaluation and consultative services on significant behavior and mental health issues.

In discussing the need for long-term residential care for people with neurobehavioral issues it is important to note that the Brain and Spinal Injury Trust Fund Commission does not support the institutionalization of people with disabilities, including people with severe behavioral issues following brain injury. The Commission recognizes that some people with more severe behavioral issues will not be able to be supported safely and effectively in the community because of the danger they pose to themselves or others. In place of institutions the Commission advocates for the development of community-based long-term residential programs that provide appropriate, specialized care for people with neurobehavioral issues in the least-restrictive setting possible.

## What happens to people with neurobehavioral issues who don't receive these services?

When even one of these four key components is missing from a state's system of care for people with neurobehavioral issues people with brain injury often end up in nursing homes, prisons, and state hospitals, or else become homeless. This is true in Georgia, where the lack of screening, training, funding for rehabilitation, and long-term supports is forcing many families to rely upon law enforcement to manage their family member's behavior, or to send their loved one to an institution either in or out of state. This is a disturbing reality for people who once led active lives and who could live successfully in the community with the proper supports.

While nursing facilities offer nursing care for geriatric residents, and sometimes individuals with disabilities who need nursing home level of care, they are generally inappropriate for younger adults who need rehabilitation and behavioral interventions. They are also inappropriate for people with neurobehavioral issues because nursing home staff do not have the expertise and training to manage behavioral issues caused by brain injury. As a result, individuals who do exhibit behavior problems often are discharged from these facilities with no other options for placement.

Caring for people with neurobehavioral issues in nursing homes is extremely problematic for two reasons. First, it is ineffective and costly. According to the University of Minnesota's Research and Training Center on Community Living, Georgia spends about \$81,000 a year for each resident in institutional care, which includes nursing homes. Nursing homes do not provide specialized care for people with neurobehavioral issues and their staff does not receive training to manage behaviors resulting from TBI. As a result, many people with neurobehavioral issues are often denied admission or discharged from nursing homes because the nursing home staff does not know how to manage the behaviors, and the lack of specialized care prevents the behavior from ever improving. With nowhere else to go, these people end up in prisons, state hospitals, or homeless. However, this same \$81,000 could be used to provide specialized, community-based care in a neurobehavioral program where people could receive appropriate care that would help to improve the person's behavior and, over time, reduce the costs of care.

Second, and more importantly, placing people in nursing homes and other institutions when they could be served in a community setting violates the U.S. Supreme Court's 1999 decision in *Olmstead v. L.C. and E.W.* This landmark decision makes states responsible for providing services in the "most integrated setting" possible, rather than in nursing homes and other institutions, in keeping with the Americans with Disabilities Act's integration mandate. States have been directed to develop a comprehensive and effective working plan for people to get services in the least-restrictive setting possible. Currently, the state of Georgia is in violation of the Olmstead decision because of the number of people with brain injury who are residing in institutions because of a lack of services and funding.

What is even more disturbing is that many people with neurobehavioral issues, particularly children, are often placed in out-of-state institutions because of the lack of services in Georgia. While this practice may be beneficial in a few situations (i.e. when there are no other in-state alternatives for the most appropriate and effective services) it is disturbing for three reasons. First, it takes the person away from their family and community and robs them of a life surrounded by people who know and care about them. Second, it is actually more costly to the state to place a person in out-of-state institutions, yet current policies actually encourage this option: under Medicaid, the program has flexibility to pay higher rates to out-of-state providers than to in-state providers. Public schools may also place a child out of state if they are unable to meet their responsibility for providing an appropriate public education because of the lack of expertise or resources to do so. Finally, it is disturbing because services and supports for persons with brain injury have evolved in many states, and it is the Commission's opinion that Georgia has not kept pace.

While many people with neurobehavioral issues end up in nursing homes, many others end up in jails or prisons. This is particularly true for people who:

- Have not been identified as having a brain injury or behavioral problems resulting from a brain injury;

## How the Justice and Correctional Systems are Bearing the Burden

K. is a good-looking man in his early 20's. He sustained a TBI when he was involved in a severe car accident when he was 19 years old. Prior to his accident K. had been a star student who had graduated from high school and was just beginning his life as an adult. He had never been in trouble. However, following his TBI K. was arrested and jailed numerous times for inappropriate behavior resulting from his TBI. His mom has worked hard to educate the judge and her son's probation officer about TBI and neurobehavioral issues. As a result, they are beginning to understand and find alternatives to jail to address his behavior.

When W. was 16 years old he was severely injured with a TBI after being struck by a car while crossing a major highway. Now, 30 years old, he is in a county jail after ramming his bicycle into a car, running away from an accident and having outstanding warrants in another county for public drunkenness.

W. has been seeing a neuropsychologist for many years to address his decreased inhibition and adjustment disorder that were the result of his TBI, a frontal lobe injury. He has trouble with anger management and substance abuse. After he became an adult, W. was able to live independently in his own apartment and maintain a job for about 6 months, with support from his mother who helped him with money management. However, as his home structure and supports decreased he struggled and ultimately was unable to live independently.

His neuropsychologist believes W. would be able to live successfully in the community if he could get at least one year of long-term residential treatment to address the behavioral issues from his TBI. However, there isn't funding to support this service, nor is there an alternative service that might provide sufficient support to him in the community. As a result, jail has become the only alternative for W.

S. is a 19 year old male who sustained a TBI at age 17 and had no prior history of drug use. As the result of his TBI S. has become involved with drugs and is involved with the legal system. S. was recently mandated into "drug court," which is a two-year commitment. His mother is seeking alternative treatment instead of punishment.

- Have no family;
- Have family who can no longer care for them because they are exhausted, burnt out, or fear for their safety; and/or
- Do not have access to appropriate services and supports.

This is not surprising or uncommon that people with TBI may end up in the justice system, given that many of them have poor judgment, insight and behavior problems that result in physical aggression or other socially unacceptable behaviors.

According to jail and prison studies, 25-87% of inmates report having experienced a TBI as compared to 8.5% in the general population who report a history of TBI. Prisoners who have had brain injuries may also experience mental health problems such as severe depression and anxiety, substance abuse disorders, difficulty controlling anger, or suicidal thoughts and/or attempts, making it challenging and costly for states to house people with brain injury in jails and prisons.

There are a number of problems with leaving the justice system to deal with people with neurobehavioral issues. First and foremost, people with neurobehavioral issues are people who are struggling with behavioral issues caused by a brain injury, which they cannot control. They are not criminals and are inappropriate for inclusion in the justice system. Second, the justice and correctional systems are oriented towards using punishment to change behavior rather than treatment, and while the behaviors of a person with neurobehavioral issues may be inappropriate or unacceptable, punishment is not likely to have an effect on changing or reducing the inappropriate behaviors. In fact, the stress of arrest and confinement and exposure to the norms and behaviors of the prison population may actually escalate the behaviors of a person with TBI. Third, the costs of housing a person with neurobehavioral issues in a jail or prison far outweigh the costs of providing appropriate support and treatment for that person in the community. Lastly, most inmates will eventually be released from prison, and a person with TBI who was incarcerated, rather than treated, is susceptible to becoming homeless, or returning to drugs and other activities that may result in a re-arrest, thus perpetuating the problem. (For additional information about TBI in prisons and jails, and for a

guide for criminal justice professionals, see Appendices E and F.)

The other place where people with neurobehavioral issues may end up is in state hospitals. While Georgia law prohibits people with brain injury from being admitted to state hospitals, many people with unidentified

brain injuries are placed there because their behaviors mimic mental illness. This, too, is an inappropriate placement for people with brain injury and will be discussed in greater detail in the next section.

Lastly, if people with neurobehavioral issues who lack services and supports do not end up institutionalized they often will end up homeless. In a recent study, 24% of homeless people interviewed reported having a brain injury. This is not surprising given that people who are at risk of becoming homeless are often in the same risk groups for brain injuries: veterans, victims of domestic violence, people with disabilities or mental illness, people with substance abuse problems, or prisoners. According to Francesca LaVecchia, Ph.D., Chief Neuropsychologist for the Massachusetts Rehabilitation Commission, in many cases, “homelessness is an extension of a downward cycle that can occur when an individual experiences a brain injury. Cognitive impairment leads to behavioral problems, money issues, and substance abuse, which all contribute to the individual’s inability to maintain a stable living situation.” The study also found that people with brain injury who are homeless “generally fare worse than homeless individuals without injuries.” For example, they are more likely to live on the streets rather than in shelters, be homeless for longer periods of time, have significantly higher rates of substance abuse or mental health issues, be at increased risk for victimization, and have more emergency room visits or hospitalizations. (For more information about how people with TBI are at increased risk of victimization, see Appendix G.)

## Summary

It is possible to support people with neurobehavioral issues in community or in the least restrictive community-based setting possible with the following components in a coordinated system of care:

- appropriate screening and identification to ensure that people receive appropriate care and services;
- specialized training for and awareness of neurobehavioral issues among caregivers and professionals to ensure sufficient supports and a workforce with expertise;
- adequate and appropriate rehabilitation to improve functioning, quality of life and the ability to live in the community; and
- sufficient funding for community-based, long-term supports to enable individuals to live as independently and productively as possible.

Ensuring proper care and preventing inappropriate placement requires that all four of the components be implemented in a coordinated system of care for people with neurobehavioral issues.



## Assessment

### *The Current Status of Georgia's System of Services for People with Neurobehavioral Issues*

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#### **What services are available for Georgians with neurobehavioral issues?**

Georgia offers a limited number of services to support people with neurobehavioral issues. These services can be distinguished between those that were specifically designed to serve people with TBI and those that were designed to serve people with other disabilities, but which can include people with significant behavior problems from brain injury. These include:

##### **Agencies with programs designed to meet the needs of people with TBI**

- Brain and Spinal Injury Trust Fund Commission
- Department of Labor, Rehabilitation Services, Roosevelt Warm Springs Institute for Rehabilitation
- Private Providers

##### **Agencies with programs designed to serve other populations but that include people with TBI**

- Department of Community Health, Office of Medicaid
- Department of Education, Division for Exceptional Students
- Department of Human Resources
  - Division of Mental Health, Developmental Disabilities, and Addictive Diseases
  - Division of Public Health, Family Health Branch, Children's Medical Services
- Department of Labor, Rehabilitation Services, Vocational Rehabilitation
- Independent Living Centers

The following section describes the services provided in Georgia for people with neurobehavioral issues in an effort to determine the level of existing infrastructure and to identify any gaps in service.

#### **Existing agencies or programs that include services and funding specifically designed to meet the needs of people with TBI:**

- **Brain and Spinal Injury Trust Fund Commission**

The Brain and Spinal Injury Trust Fund was created by legislation in 1998 to provide funds to assist both people with TBI and people with spinal cord injury (SCI) with the costs of receiving care and rehabilitative services. People with TBI can apply for funding for a range of services and goods, including housing, health care, personal assistance, assistive technology, transportation, respite, recreation, and rehabilitation. However, because annual revenue for the Trust Fund averages only about \$1.8 million each year the Commission, which oversees distribution of the Trust Fund, is limited in the number of people it can assist and is not able to pay for long-term care. The Trust Fund is not an entitlement, and the maximum award is limited to \$15,000 in one year, although most awards are limited to \$5,000 per year. It should be noted that the Trust Fund is the only state funding source that is dedicated to meeting the needs of people with TBI.

In distributing the Trust Fund the Commission realized that it is the only state agency in Georgia that is specifically dedicated to meeting the needs of people with TBI. Although the Department of Human Resources has Offices of Mental Health, Developmental Disabilities, and Addictive Diseases there is no similar office for people with brain injury, even though brain injury affects a significant amount of our state's population. The Commission also recognized the need for improved data and coordination of services for people with TBI and SCI to facilitate long-term planning and stewardship of the Trust Fund. In 2003, the Commission took over the role of Lead Agency on Traumatic Brain & Spinal Injuries for the state of Georgia from the Department of Community Health, recognizing that the role matched the Commission's statutory authority to recommend public policy to the Governor

and General Assembly. As the Lead Agency the Commission is charged with assessing the needs of people with TBI and SCI and making recommendations to the Governor, legislature, and state agencies for the improvement of services for people with TBI and SCI. The Commission is thus in the process of completing a formal Needs Assessment & State Action Plan, which will include some of the findings from this report.

In 2004 the Commission also took over administration of the state's Central Registry for Traumatic Brain & Spinal Injuries, the state's service registry that tracks the number of people with TBI and SCI who were treated in a hospital setting, and which provides information about available resources to them soon after injury. Seventeen other states have a similar registry for TBI. The Commission uses the data for long-term planning, both for distributing the Trust Fund as well as developing public policy in its role as Lead Agency.

- **Department of Labor, Rehabilitation Services, Roosevelt Warm Springs Institute for Rehabilitation**

Currently, the only program that the Department of Labor has developed to meet the specific needs of people with TBI is the Roosevelt Warm Springs Institute for Rehabilitation and Vocational Rehabilitation. The Institute is a medical and vocational rehabilitation facility that specializes in brain injury and offers both short- and long-term acute care and outpatient services. (A description of the Department's Vocational Rehabilitation program, which serves all people with disabilities including TBI, is provided in the next section.)

- **Private Providers**

In addition to the state agencies that provide specialized services for people with TBI, there are a handful of service providers and nonprofit organizations in Georgia that provide services specifically designed for people with neurobehavioral issues. These include:

- Rehabilitation hospitals that specialize in treating people with TBI, such as Children's Healthcare of Atlanta, Emory Center for Rehabilitation Medicine (Atlanta), Memorial Hospital (Savannah), Shepherd Center (Atlanta), and Walton Rehabilitation Center (Augusta) (a few acute care hospitals include specialized services for people with brain injury, although generally these services are limited and do not provide the range of care that is provided by the rehabilitation hospitals);
- Restore Neurobehavioral Center, an Atlanta-based for-profit program that is the only specialized long-term residential treatment center and long-term supported living program for people with neurobehavioral issues in Georgia;
- Jimmy Simpson Foundation, a private non-profit community-based organization that provides residential care to people with TBI who need 24 hour a day care (serving up to 12 people) as well as a day program (serving up to 20 people);
- Side-by-Side Brain Injury Clubhouse, an Atlanta-based non-profit day program that provides psychosocial and vocational rehabilitation for people with brain injury, and which has the capacity to serve 40 people at one time;
- Brain Injury Association of Georgia, a non-profit organization that provides education, advocacy, and support services to people with brain injury, family members, and service providers; and
- Georgia Advocacy Office, a private non-profit corporation that investigates allegations of abuse and neglect on behalf of people with disabilities by Congressional mandate and state designation, and which includes a program to address the specific needs of people with TBI who are subject to abuse and neglect, particularly in psychiatric institutions and nursing homes.

While the services that are provided by these programs are of high quality and well regarded they do not have the capacity to serve the large number of Georgians who need specialized neurobehavioral services. More services are needed.

## **Existing agencies or programs that include services and funding specifically designed to serve other populations, but which can include people with significant behavioral issues from brain injury:**

State agencies and private programs that serve people with other disabilities may also serve individuals with TBI, but in general they will be diagnosed under a category other than TBI in order to qualify for services. This means that people with TBI who are diagnosed under another category will receive services that were designed for that category, which may not always address the needs of people with TBI. In many instances, however, individuals with brain injury are excluded from these services due to eligibility requirements relating to diagnosis or the age of the person at the time of injury.

Examples of other state agencies or programs that may include people with neurobehavioral issues in their services are:

- **Department of Community Health, Office of Medicaid**

The Office of Medicaid offers four Home and Community-Based Services (HCBS) waivers that are designed to provide funding to support people who are aging or have disabilities in the community. All four of the waivers were designed to assist eligible people to return to the community from institutional care or to remain in a community-based living setting for as long as possible. In addition to the “core services” that are offered by all of the waivers (including service coordination, personal support, home health services, emergency response systems, and respite care) each waiver program offers additional services particular to the specific waiver:

- *Community Care Services Program (CCSP)*  
CCSP was designed for people with limited incomes who are elderly and/or people who have functional impairments or other disabilities. In addition to the core services CCSP provides funding for adult day health care, alternative living services (such as a personal care home), or home-delivered meals.
- *Deeming Waiver (formerly Katie Beckett Waiver)*  
The Deeming Waiver was designed for children with disabilities who would not otherwise qualify for Medicaid because of their parents’ income and resources. To qualify for the waiver, a child must be under the age of 18, meet Social Security disability criteria, and be ineligible for Supplemental Security Income (SSI) because of their parent’s income or assets.
- *Independent Care Waiver Program (ICWP)*  
ICWP was originally created to meet the needs of people with significant physical disabilities who needed 24-hour care, but eventually ICWP expanded its eligibility criteria to include services for people with TBI. To be eligible for the program, a person must have a severe physical disability or TBI, be between the ages of 21 and 64, and be Medicaid eligible or potentially Medicaid eligible. In addition to the core services, ICWP provides funding for the following: behavior management services, specialized medical equipment and supplies, counseling, and home modifications.
- *Mental Retardation Waiver Program (MRWP)*  
MRWP was designed for people who: are eligible for Medicaid; have had mental retardation since birth or before age 18, or who have another developmental disability since birth or before age 22, which requires services similar to those needed by people with mental retardation; live in an institution for people with mental retardation or developmental disabilities or are at risk of being placed in such an institution. MRWP is administered by the Office of Developmental Disabilities. In addition to the core services MRWP provides funding for day habilitation and supported employment, residential training and supervision, specialized medical equipment and supplies, vehicle adaptations, and home modifications.



While all of the waiver programs can serve people with TBI, only one of them (ICWP) is actually designed to do so. The other three have various limitations that prevent people with neurobehavioral issues from getting adequate and appropriate care. For example, people with TBI can potentially qualify for the MRWP waiver if they sustained their injury before the age of 22, however, in order to qualify for it they must be able to prove that they have: a life-long, chronic disability; substantial functional limitations in 3 or more of the following areas: self-care, understanding and use of language, learning, mobility, self-direction, and capacity for independent living; and an IQ of 69 or lower. There is some question about whether the criteria regarding IQ might be waived for people with TBI. If it is not then most people with TBI would not qualify for this waiver. While MRWP offers some behavior management services these services are designed for people with developmental disabilities and are inadequate for addressing neurobehavioral issues for people with brain injury.

It should be noted that the Office of Developmental Disabilities has recently revamped the MRWP waiver in an effort to give people more control over the ways in which their waiver dollars are spent and to provide greater options for services and supports. The current waiver will change to the New Options Waiver (NOW), which provides support to people who do not need 24 hour care, and the Comprehensive waiver for people who do need 24 hour care. The design of the new waivers reflects the desire of the Office of Developmental Disabilities to ensure that people with developmental disabilities have the funding and support they need to live in the community. Budgets for the waivers will be based upon the individual's needs rather than on a pre-defined cap and the family has the ability to choose innovative ways to support their loved one in the community. As of the writing of this report, it is anticipated that the new waivers will go into effect in January, 2008.

The CCSP waiver is primarily designed to address medical issues for the elderly and people with physical disabilities through home health services, attendant care, adult day health care, etc. Most people with neurobehavioral issues do not need assistance with medical care but instead need behavioral support for brain injury, which is not covered by these waivers. The only behavioral support that is provided by this waiver is through adult day programs for elderly people with Alzheimer's disease and other types of dementia, but the environment, strategies, and interventions used in these programs are inappropriate and ineffective for people with TBI, particularly young people with brain injury.

## When ICWP Fails People with Neurobehavioral Issues

S. is a woman with TBI who was enrolled in ICWP. The Program referred S. to an adult day program for people with TBI, however, the program director observed visible signs of self-injury, hallucinations and delusional thinking. The director said that she would only allow S. into the program if she received medication management from a psychiatrist and was accompanied by a personal attendant to help manage her behaviors. Since the costs of these required services would exceed the level of services allowed by ICWP, S. was denied admission to the day program.

While S. clearly needed neurobehavioral services to assist her, these services were also not available to her through the ICWP because the cost of adequately trained personal support staff exceeded the program cap, and because there are no ICWP providers of community-based neurobehavioral programs in Georgia.

Soon, S. assaulted her untrained personal support staff and was committed to an inpatient state mental health facility where she remained for 9 months at great cost to the state. Since she was hospitalized for over 90 days, the ICWP discharged her from the program and S. lost her waiver benefits. A law firm represented her for free in an appeal to reinstate benefits and eventually won. ICWP reinstated her benefits and assigned her a new waiver case manager, who found a caregiver for S. who was willing to provide care in a host home. Funding from the waiver program is inadequate to cover the full costs for the caregiver or for adequate training in behavioral supports. S. now attends the TBI adult day program but must bring a personal support provider to assist in managing her behavior.

C. was a thriving high-school sophomore when he was severely injured in a car accident in 2001. He was life-flighted to a trauma hospital where he remained in a coma for three weeks. After being transferred to an Atlanta-based specialty hospital for brain injury C. was eventually brought out of the coma and began

(In addition to the four waivers the Office of Medicaid administers the Service Options Using Resources in a Community Environment Program [SOURCE]. SOURCE is similar in its design and core services as the CCSP waiver; however, unlike the waivers, SOURCE is an entitlement program. Unfortunately, the current lack of funding restricts its use for the very poorest of people. For reasons similar to the CCSP waiver, SOURCE is generally not a suitable option for people with neurobehavioral issues.)

The waiver that is best designed to serve the needs of people with neurobehavioral issues is the ICWP. Indeed, it has the capacity to provide the most appropriate types of services and supports and thus assist many people with brain injury to live successfully in the community. This is because it includes behavioral management services that are specifically designed for people with TBI in its list of covered services.

Unfortunately, there are significant flaws in the way that the ICWP is administered that prevent Georgians with brain injury from receiving the care they need to be able to live in the community. The flaws in the program all relate to the way in which costs are calculated for the waiver. Federal Medicaid regulations require that the total cost of providing care for the person in the community must not be more than the cost of providing care for that person in a hospital or nursing home. This means that the Office of Medicaid must calculate the average costs of care for someone in a nursing home and use that amount to cap the costs of providing services in the community via a waiver. This is problematic for people with neurobehavioral issues because generally the nursing home level of care does not cover the costs of neurobehavioral management. In fact, nursing homes do not provide appropriate behavioral management services for patients with TBI; if they did, the nursing home level of care for people with neurobehavioral issues would be higher. Thus, by its very design the formula for establishing limits for the ICWP prevents people with neurobehavioral issues from receiving the care they need to remain in the community.

Given that, however, Georgia's Office of Medicaid has recently developed its own formula for the ICWP and has instituted a cap of \$45,567 per year for all costs for people who would qualify for nursing home level of care, and \$90,000 for people who qualify for hospital level of care. To date, however, most of the people with TBI who participate in ICWP have been placed under the lower rather than higher cap. This has meant that people with neurobehavioral issues who require intensive behavioral management services and 24-hour support cannot be served by the ICWP because the total

the arduous and painful task of relearning to walk, talk, eat, and perform other basic activities. It wasn't until C. began to participate in the hospital's outpatient program that he had his first violent episode, and his behavior continued to escalate after that, posing a significant risk to himself and others.

In the beginning it was fairly easy to get assistance for his behavior problems since C.'s private insurance paid for him to be admitted to the state's only inpatient rehabilitation center for people with neurobehavioral issues. Unfortunately, the insurance coverage did not cover the time period necessary to address his issues, so C. was discharged to the care of his mother in August, 2002. That was the point at which it became extremely difficult for his mother to get the necessary assistance for her son. It was clear that she could not manage C.'s behavior by herself and that he still needed additional rehabilitation.

C.'s mother spent nine months trying to get assistance from ICWP, the Office of Mental Health (MH), and anyone else who would listen but none of these agencies would agree to provide services or funding. Meanwhile C.'s mother often had to call the police for assistance because she had no other way to ensure C.'s or her family's safety. During this time C. was in and out of both private- and state-funded mental health facilities as well as a residential setting for people with brain injury, where he was eventually discharged because of his aggressive behavior. It wasn't until C.'s mother called Representative Nathan Deal's office that ICWP finally agreed to pay for C. to be re-admitted to the inpatient rehabilitation center.

Throughout the time C. was at home and in the rehabilitation center, C.'s local school system made efforts to serve C. in the community, but eventually decided to pay for C.'s placement in a residential facility rather than continue to try to manage his behaviors in the local school setting. Since the school system was providing the funding for placement, ICWP discharged C. from their program. Unfortunately, one of the few programs that was available and that would accept the funding source was an out-of-state program that specialized in developmental disabilities

costs of these services would exceed the cap. This has had catastrophic effects on people with brain injury, many of whom have had to be admitted to a nursing home or ended up in a prison or state hospital. The irony is that nursing homes generally do not have staff that is trained to manage neurobehavioral issues and often end up discharging people with neurobehavioral issues. There are many people with neurobehavioral issues in Georgia who have been denied admission by every nursing home in the state. Truly, these people have no place to go and are at even greater risk for ending up in a prison or state hospital or homeless.

Although the ICWP was designed to provide services that are most critical to people with neurobehavioral issues in its current incarnation the ICWP cannot do this. This is certainly because of the \$45,000 cap that has been instituted but it is also for other reasons. First, ICWP has set the rate of qualifications too high and the rate of reimbursement too low for providers of this service. As a result, most providers of behavioral management services are unwilling to serve people with TBI whose only form of payment is through the ICWP. Second, the ICWP does not include options for long- or short-term residential neurobehavioral services because they do not consider such programs to be community-based resources. However, for many people with severe neurobehavioral issues the only way that they can safely live in the community is if they have access to neurobehavioral rehabilitation programs that can provide a foundation for long-term behavioral management in the community. In addition, while it appears that neurobehavioral rehabilitation is costly over time it has proven to reduce the costs of supporting a person with TBI in the community because the person had received rehabilitation and management strategies for the unwanted behavior. In one person's case, the costs of supporting a person with neurobehavioral issues were reduced by \$40,000 in one year after receiving appropriate rehabilitation. In the end, the choice becomes whether to invest upfront in the services necessary to allow a person to live safely in the community, ultimately at a lower cost, or whether to pay for the higher costs of inappropriate institutionalization over a lifetime. Lastly, the ICWP does not offer centralized and coordinated assistance to help people identify where and how to get services as other waiver programs do. This makes it very difficult for people to access the services for which they are eligible.

In order for people with neurobehavioral issues to live in the community it is critical that the ICWP be reformed so that it can fulfill its original intent to provide services for people who need intensive, 24-hour supports in order to remain in the community. The fact that people with disabilities and their caregivers have been struggling with the ICWP for the past ten years indicates that the program has significant flaws that prevent it from providing the most appropriate and critical services to allow people with significant disabilities to live in the community.

rather than brain injury, which meant that C. would not get further assistance for his neurobehavioral issues. Essentially, since July 2004, C. has had to live in an inappropriate setting in a location far from his loved ones, which has only exacerbated his condition rather than improved it.

The problem now is what to do with C., who turns 22 and will be discharged from the out-of-state program and returned to Georgia in October 2007. In an attempt to plan ahead for his care his mother began in August 2006, to secure funding and services for C. This meant re-contacting and repeating the laborious application processes for all of the state agencies with which she had previously dealt. This time, in addition to MH and ICWP, C.'s mother also requested assistance from the Office of Developmental Disabilities. However, again, C.'s mother faced a system in which no agency would agree to provide services for her son: DD said that C. does not qualify for their services because his I.Q. is too high. MH denied services for C. because his behavioral problems are the result of a brain injury rather than mental illness. The only program whose eligibility criteria C. did meet was ICWP, but the program refused to provide services to him citing C.'s violent behavior, the need for 24-hour care that would exceed their \$45,000 cap on services, and their belief that C. could not be supported in the community. As a result, there are no options for C. once he returns to Georgia in the fall. Because of the lack of options for care for her son C.'s mother was forced to make the very difficult and painful decision not to apply for legal guardianship for her son. This means that the responsibility for his care will fall upon the state when he returns in October.

To ensure that the ICWP is sufficiently reformed to meet the needs of Georgians with disabilities, and particularly people with neurobehavioral issues, requires:

- Providing additional funding to support the number of people who need ICWP and to eliminate existing waiting lists;
- Removing the caps of \$45,567 and \$90,000 and instead setting budgets based upon the individual and particular needs of each person;
- Increasing the rate of reimbursement for providers of behavioral management services; and
- Including coverage for long- and short-term neurobehavioral residential rehabilitation programs.

The two new waivers designed by the Office of Developmental Disabilities offer an excellent model for redesign of the ICWP waiver, where the focus is on providing funding based upon the individualized and particular needs of the individual. Besides allowing for individual budgets rather than a one-size-fits-all cap, the NOW and Comprehensive waivers plan to provide sufficient funding for a variety of services that are necessary to support people with behavioral issues, including behavioral supports, “community guides” (similar to service coordinators), community residential alternatives, community living support (similar to personal support), natural support training to train personal support personnel, and professional therapeutic services. All of these services can and should be included and adequately funded by the ICWP.

If the ICWP cannot be reformed to meet its original intent then the Commission recommends following the example of 22 other states and creating a TBI-specific waiver that is designed for the sole purpose of supporting Georgians with brain injury, particularly people with significant behavioral issues, in the community or in the least-restrictive setting possible. For example, the state of Minnesota has developed a new TBI waiver to cover services that would have been provided in a nursing home and includes additional funding to provide rehabilitative services. This waiver provides a heavy emphasis on behavioral supports for persons with cognitive and behavioral issues. The waiver has two levels of care: TBI-NF (specialized nursing facility) and TBI-NB (neurobehavioral hospital). The menu of services is not different between them, but rather the amount of available resources/services varies based on intensity of need.

- **Department of Education, Division for Exceptional Students**

As previously stated, children and adolescents who sustain a brain injury at a young age may demonstrate behavioral symptoms long after the time of the injury. Most likely these children are enrolled in school by the time the behaviors begin to appear. If a student is in the general education system when this occurs, the school system will provide academic and/or behavioral interventions using a model called the Georgia Student Achievement Pyramid of Interventions, a three-tiered system that monitors student performance and behavior and provides progressively more intensive support and interventions as needed in the general classroom. The highest or most intensive level of support involves a Student Support Team (SST) to assist the student. This team is typically comprised of a group of school personnel with an array of expertise such as administrator, regular education teacher, special education teacher, school social worker, a parent, a media specialist, a school psychologist or other central office persons. The SST analyzes the student’s academic and behavioral patterns and develops a plan to support the student in the general classroom. If the student continues to struggle in the general classroom the SST can refer the child for special education services for further support.

In identifying students with special needs who require special education services the state Department of Education (DOE) refers to the Georgia Rules to determine eligibility. The Georgia Rules list TBI as a disability category for special education, while children who have brain injury caused by ABI (see page 8) are eligible for services under the category of *Other Health Impaired*. To determine whether a student is eligible for diagnosis of TBI the school system will evaluate: a child’s pre-injury functioning status; verification of the TBI through medical reports; and a



neuropsychological, psychological or psychoeducational evaluation that addresses the impact of the TBI on the child's various functions.

For many reasons, however, children with TBI are not being identified in the school systems. This is evidenced by the fact that the state's Central Registry for Traumatic Brain & Spinal Injuries identified 17,067 children between the ages of 5 and 19 who sustained a TBI and were treated in a hospital in Georgia in 2005. These numbers are compared with the Department of Education's statistics, which identified a total number of 447 students with TBI in 2007. The following contributes to the lack of identification:

- Schools must rely upon parents to provide the medical diagnosis of TBI in order to obtain school supports in this category. In some cases, parents fail to notify the school system that their child has sustained a brain injury because they do not recognize the connection to the child's injury and his/her performance in school. Other times, parents fail to notify the school system because they are in denial about the extent of their child's injury, or fear the stigma related to special education services.
- Children whose families might be very interested in special education services may have some difficulty in establishing their child's eligibility. There are two ways to establish service eligibility: one is to provide medical documentation of the injury. This is accomplished by requesting hospital records. For children who sustain their injury at a young age these records may no longer be available. In these cases families may choose the second option and request a neuropsychological evaluation. While most schools are staffed by school psychologists who assess children for special education eligibility, they do not have a neuropsychologist who has expertise in brain-behavior relationships and can conduct such an evaluation. The services of a neuropsychologist are expensive and require medical insurance coverage or referral by the school in order to cover the costs. Families face obstacles for both types of funding, especially if the behavioral symptoms appear several years post injury.

As a result, many children with TBI who display behavioral symptoms as their first sign of the injury are diagnosed with the incorrect category of *Behavior Disordered* instead of TBI. This mistaken diagnosis can lead to inappropriate placement or services that can exacerbate the student's behavioral problems.

Another reason that proper identification of TBI in children is critical is that people with TBI often experience other physical impairments, such as loss of vision or hearing, as a result of the brain injury. These impairments can significantly impact their ability to function in the classroom and may also lead to behavioral problems if they go undiagnosed. In a recent example, a child with TBI was exhibiting behavior that seemed inappropriate to his teachers, including holding his head at an odd angle throughout class. His teachers thought that he was being difficult and repeatedly reprimanded him or sent him home early for "bad behavior." It wasn't until a nurse case manager with expertise in brain injury identified both his TBI and the fact that he had some degree of blindness in both eyes that the school understood that his behavior and head-tilting were ways of compensating for the vision loss. The school is now working with the child's family to ensure that he has the proper supports to address his brain injury and vision loss in the classroom.

In addition to misdiagnosis, the other problems that prevent children with TBI from being successful in the school systems are a lack of training and a lack of coordination with families and other services. Given the independence of local school systems, the Georgia DOE does not have the authority to require training on TBI for regular and special education teachers, counselors, nurses, and administrators at the local level. As a result, the majority of professionals in the school systems receives no training in TBI and is ill-equipped to address the needs of students with TBI, even though children are in one of the highest risk groups for TBI. The DOE has identified the need for training on TBI and is collaborating with the Commission to provide opportunities for ongoing training for local educators.

In addition to the lack of training there are limited mechanisms for coordinating with families to ensure a continuum of services and successful transitions for children with TBI from home to school, and from school to work or higher education. If a student is in special education then the school system is required by law to develop a plan with their families and teachers for transitioning out of high school after graduation. Generally the schools do this well. However, if the student is not in special education they will not have an opportunity to develop such a plan.

Due to the increase in school violence in recent years schools have developed strict policies for discipline around serious misconduct. Students with serious misconduct are generally placed in disciplinary programs, including alternative school settings that are tied to the juvenile justice system. There have been times when a student with neurobehavioral issues has been placed in these programs rather than being evaluated and having appropriate interventions implemented to address the neurobehavioral issues. This is, in part, because these programs do not currently have a method for reviewing the child's medical history to determine whether TBI is a contributing factor to the misconduct. In these cases the school personnel and parents/guardians determined that there was a reasonable cause to bypass the SST process and followed established policies for this process. For children whose behavioral problems are particularly difficult to manage, the prognosis is even worse in Georgia: because of the limited number of options for neurobehavioral inpatient treatment for children in this state, schools often place these children in costly out-of-state programs for treatment, separating them from their homes and communities. When these children turn 22 years old they are discharged from the out-of-state programs and returned to Georgia, often with no options for long-term care and support, including the ICWP (see C's story on pages 25-27). When this happens their behavior may regress and they may end up institutionalized at a young age.

The burden to improve the situation for students with TBI lies both with the parents and the school systems. Parents and caregivers can help their children by sharing medical information with the school at every opportunity to ensure correct diagnosis in a timely manner. Similarly, the school systems must develop mechanisms for screening and identification of TBI, particularly for instances when parents are unsure of the link between their child's behavioral problems and a previous injury, or are fearful of sharing such information. It would be appropriate for the DOE to develop training and screening tools to guide school personnel, particularly members of the SST, to help identify situations when further inquiry of a student's medical history is warranted. The Iowa Department of Education has created Brain Injury Resource Teams at each Area Education Agency (AEA) to meet the needs of children with brain injuries. In addition, a Brain Injury Resource Team from the Center for Disabilities and Development at the Children's Hospital of Iowa provides consultation to the AEA teams. These teams collaborate to provide consultation for children who have sustained a recent brain injury or were injured in the past, and consultation for their families, and local school personnel.

- **Department of Human Resources**

- Division of Mental Health, Developmental Disabilities and Addictive Diseases**

- *Office of Mental Health*

- As noted above, some individuals with TBI will have dual diagnoses, meaning that they will simultaneously suffer from the effects of TBI and mental illness, problems with alcohol and drug use, or other medical or physical disorders. Some of these issues may have been present prior to the injury, while in other situations they manifest after the injury. Given the challenging nature of neurobehavioral issues and the ways in this can be complicated by a dual diagnosis, it is not uncommon for families of people with TBI to seek out services in the mental health system.

- In Georgia, the Division of Mental Health, Developmental Disabilities and Addictive Diseases has prioritized eligibility for its services to those with serious and persistent mental illnesses, such as schizophrenia, major depression and bi-polar disorder. Under the adult "Core Customer" definition, adults age 18 and older seeking assistance for mental health or addictive disease services must have a behavioral health diagnosis on Axis I, in accordance with the latest edition of the DSM (Diagnostic and Statistical Manual of Mental Disorders),

## **When People with TBI are Excluded from Mental Health Services**

J.L. became violent for the first time a few months after suffering a TBI. Following up on the recommendation of a hospital, J.L.'s family called a private provider after J.L. violently assaulted a family member and threatened to kill himself as well. The private provider referred J.L. for an involuntary commitment process (to determine danger to self and others) for possible admission to a state mental health facility. However, within the 48-hour time frame he was released from the facility because he had a TBI, not mental illness. Because his behaviors were too risky for the home his family continued to try to find assistance for J.L. but were unable to because of a lack of funding and available services. The family had no choice but to force J.L. to leave their home. He was soon arrested for his continuing violent behaviors. No one knows what has happened to J.L. since then.

and a level of functioning that is significantly affected by mental illness or addictive disease. This means that individuals with traumatic brain injury are not eligible for services, although they may be receiving services as the result of another diagnosis.

In addition to this emphasis on serious and persistent mental illnesses, people with a primary diagnosis of TBI are specifically prohibited by statute (OCGA 37-3-1) from receiving state mental health services. While this prohibition was developed to avoid inappropriate institutionalization it has prevented people with a dual diagnosis of TBI and mental illness from receiving appropriate mental health services. Further, it excludes people with TBI from the involuntary commitment laws even though involuntary commitment may be necessary when the person with brain injury poses a danger to self or others.

Faced with a similar problem, the state of Alaska's mental health agency broadened its mission and services to include individuals with traumatic brain injury who have neurobehavioral problems. The state Medicaid plan offers case management and skills development to support these individuals, and also offers both clinic and rehabilitation options for those who are also Medicaid eligible. These services include:

initial intake assessment; semi-annual intake assessment; psychiatric assessment; neuro-psychological testing and evaluation; individual, family and/or group psychotherapy; pharmacologic management; crisis intervention; medication administration; case management; individual and/or group skill development; family skill development (for ages under 21); and day treatment.

While people with TBI are specifically excluded from admission to Georgia's state mental health programs, there a number of people with TBI who do end up in the mental health system, including state hospitals, because of improper diagnosis or forensic commitment after arrest. Since significant behavior issues from brain injury often mimic mental health issues it is not surprising that people with TBI are often misdiagnosed with mental illness. However, although it may be appropriate for people with dual diagnosis to be served by the mental health system generally the mental health system is not an appropriate place to serve people with neurobehavioral issues. As previously stated, the lack of training in TBI, and the interventions and medications that are designed to treat mental illness prevent people with TBI from being adequately served in the mental health system.

### **Division of Public Health, Family and Child Health Branch**

#### **○ Children's Medical Services**

The Family and Child Health Branch administers the Maternal and Child Health Title V program that serves children and adolescents with special health care needs. This program, called Children's Medical Services (CMS), directly provides or coordinates specialty medical evaluations and treatment for eligible children (birth to age 21) with chronic medical conditions. CMS provides or pays for comprehensive physical evaluations, diagnostic tests, inpatient/outpatient hospitalization, medications and other medical treatments, therapy, durable medical equipment, hearing aids, and dental care related to the child's CMS-eligible condition.

Currently, CMS does not include a category for children with TBI. Instead, children with brain injury may sometimes qualify for medical and health care services under the state's Medicaid or Children's Special Health Care Needs or Developmental Disabilities program.

- **Department of Labor, Vocational Rehabilitation**

Vocational Rehabilitation (VR) is a statewide program that provides services to help people with disabilities “prepare for, start, and maintain competitive employment.” Through its 13 regional offices and 54 local-level offices VR counselors offer a range of services to assist people in finding work, including counseling; supported employment; work readiness training; college, university, vocational or technical school training; and job coaching.

Beginning in the early 1990’s VR recognized the particular needs of people with brain injury and partnered with the Georgia Head Injury Association (now the Brain Injury Association of Georgia) to secure funding for a specialized employment program in 1994. With the funding VR developed the Head Injury Program, a dedicated, comprehensive, holistic and interdisciplinary program for people with brain injuries who wanted to work. The Program was comprised of 5 components:

- Roosevelt Warm Springs Rehabilitation Institute (described above), which helped to stabilize people with brain injury to the point that they could consider community re-entry and vocational options;
- Central Registry for Traumatic Brain and Spinal Injuries (now administered by the Commission), which identified people with TBI who were treated in a hospital setting and referred them to the VR counselor in their local community;
- Head Injury Transitional Program, located at the Institute, which referred people with brain injury who were returning to the community to the VR counselor in their local community;
- Head Injury Day Treatment facility, which provided vocational rehabilitation and counseling to people in a day program setting; and
- VR field teams, which included a Senior Counselor who specialized in head injury rehabilitation, a Counselor Associate, and a Secretary. These teams were located in each district and served only people with head injuries who were seeking employment.

By all accounts the Head Injury Program was very successful, effectively assisting hundreds of people with brain injury to return to work. Unfortunately, in the state’s push to privatize services in the late 1990’s funding for the Program was cut and the Program was eliminated.

Although certain components of the Program still exist, including the Institute, Central Registry, and Transitional Program, what is missing is the specialized and comprehensive approach to brain injury. Today, VR is using a generalized service model to assist people with all types of disabilities. As a result, it is not able to address the particular needs of people with cognitive disabilities such as brain injury who are seeking employment.

The most critical element of the former Head Injury Program that is missing today is the VR field team that specializes in brain injury. Because VR counselors are the key link between a person and a job, determining eligibility, developing a plan for employment, assessing for job readiness, and providing support, it is critical that they understand the specific needs of people with brain injury who are seeking employment. However, as a matter of practice VR does not provide or require training in brain injury for its counselors. As a result, many people with brain injury report significant challenges in trying to get a job through VR. In some cases, people with brain injury are told by their VR counselors that they are “unemployable,” although these same people are later able to find successful employment with the assistance of other organizations. This often happens because people with TBI require an extensive amount of time to prepare for a job post-injury, primarily because they still remember the job and skills that they had before their injury and cannot, without a lengthy process of training and rehabilitation, accept their new limitations and adapt to a new role and set of skills. In addition, once they have secured employment they need ongoing, long-term support to ensure that they are able to maintain the job.

This is not to say that VR does not provide support to people with disabilities who need jobs or follow-up once they are employed. Indeed, VR provides funding for counseling, work-readiness training, supported employment and job coaching and other services. VR also provides for follow-up and offers additional assistance if a person loses their job. While on the surface it would appear that



these services are sufficient to assist a person to become successfully employed, and certainly they are effective for many people with disabilities, without specialized training in brain injury and without services that are specifically tailored to the needs of people with brain injury they are generally not helpful to people with TBI in gaining or maintaining employment. This is especially true for people with neurobehavioral issues who require more intensive, specialized support to return to work. Granted, many people with neurobehavioral issues are unable to return to work because of the severity of their behavioral problems, however, a number of them could work if given the proper supports. To do this, VR would need to re-establish the specialized field teams and the dedicated approach to meeting the particular needs of people with brain injury so that counselors who work with people with neurobehavioral issues have the necessary training, policies, and tools available to assist them. Any funding that would be required to do this would increase the effectiveness of VR's services to people with brain injury, enable more people with brain injury to return to work, and draw down additional federal matching dollars to make this approach cost-effective.

- **Independent Living Centers**

Centers for Independent Living (CILs) are non-residential, community-based organizations, governed and staffed by people with disabilities, which offer a wide variety of services to consumers with disabilities and their families. The foundation of these services is the peer-to-peer relationship, where people with disabilities act as mentors for other people with disabilities, showing them by example how to help themselves and to live independently. Currently, there are 8 CILs in Georgia. All CILs provide the following core services:

- Individual Advocacy and Systems Advocacy
- Peer Counseling
- Information and Referral
- Independent Living Skills Training

In addition to these core services each CIL provides other services depending upon the needs of the communities they serve, including home modifications, assistive technology, etc.

While Georgia offers a few specialized services for its citizens with neurobehavioral issues, in general there are insufficient services and funding for them. Due to these service gaps, Georgians with TBI who have significant behavioral issues are either not served or are inappropriately institutionalized.

## What are the costs of these service gaps?

The state of Georgia is losing a significant amount of dollars in terms of lost productivity, duplicated services, and out-of-state and/or inappropriate placements as the result of its lack of service coordination for people with neurobehavioral issues. Consider the story of B. (pages 6-7) and the costs of his care to date, compared to the costs of more appropriate, specialized services that would have allowed B. to return home in months, rather than years:

Costs of Actual, Inappropriate Services for B.			Costs of Appropriate Services for B.		
Time spent	Service	Cost	Time needed	Service	Cost
425 days	Regional medical center: \$1300/day	\$552,500	90 days	Regional medical center: \$1500/day*	\$135,000
70 days	Specialized brain injury rehab hospital: \$1100/day	\$77,000	45 days	Specialized brain injury rehab hospital: \$1100/day	\$49,500
330 days	Out-of-state neurobehavioral program: \$600/day	\$198,000	150 days	Out-of-state neurobehavioral program: \$650/day*	\$97,500
<b>Total costs of inappropriate care:</b>		<b>\$827,500</b>	<b>Total costs of appropriate care:</b>		<b>\$282,000</b>

**Difference in costs to the state in dollars: \$545,500**

**Difference in number of days of service to B. and his family: 540**

*\*The costs listed are only averages of what the total cost of care may be, and by no means reflect the daily rate of a particular hospital or program. The variations in costs of care listed in the chart are meant to*

*illustrate the difference between the costs of actual services provided to B. and the estimated costs of providing appropriate services for him. It is important to note that costs of care vary depending upon the needs of the individual person.*

It would be easy to dismiss B.'s case as extreme, however, his experience is representative of thousands of Georgians who develop serious behavioral issues as the result of TBI. Adequate, specialized services for people with neurobehavioral issues do not exist in the state of Georgia. As a result, people with neurobehavioral issues are being cared for in ways that are costly, inefficient, and ineffective, resulting in the waste of millions of dollars to the state and its taxpayers.

The bottom line is this:

- Brain injury is a significant public health issue for the state of Georgia.
- Currently, the only dedicated funding source for Georgians with brain injury is the Brain and Spinal Injury Trust Fund. Funded by surcharges on DUI fines, current revenue for the Trust Fund averages around \$1.8 million per year. As the only dedicated funding source for people with brain injury this is grossly inadequate and prevents the Brain & Spinal Injury Trust Fund Commission from being able to address the long-term care needs of people with neurobehavioral issues in any significant way.
- Currently, there is no service system designed to serve Georgians with brain injury. Existing service systems such as Developmental Disabilities, Mental Health and Corrections are inappropriate for people with brain injury. There is no similar service system for people with brain injury. The only state agency that is currently dedicated to addressing the needs of people with TBI is the Brain and Spinal Injury Trust Fund Commission.
- The only waiver that is designed to serve people with brain injury is seriously flawed and is causing many Georgians with brain injury to be institutionalized inappropriately.
- Many people with TBI do not qualify for Medicaid waiver programs because of their income, yet they cannot afford to pay for long-term care, particularly when it requires support for neurobehavioral issues, because private insurance does not cover this.

Providing sufficient, specialized services for people with neurobehavioral issues does not require an appropriation of millions of new dollars. Many of the dollars are already there. The problem is that the necessary funds are currently being used to support the consequences of serving people with TBI inappropriately in nursing homes, prisons, and state hospitals. The costs of serving people in these settings include:

Setting	Cost
<b>State Hospital</b> – Maximum Security	\$427/day (\$155,855/year)
<b>State Habilitation Center</b> – Developmental Disability	\$299/day (\$109,135/year)
<b>State Hospital</b> – Children & Adolescents	\$488/day (\$178,120/year)
<b>Georgia Correctional Facility</b>	\$41.62/day (\$15,191/year)

People with neurobehavioral issues do not belong in our nursing homes, prisons and state hospitals. The funds that are being used to house them in these settings should instead be redirected to follow them and support them in the community. If these dollars are used under Medicaid to support people then the state will also draw down additional dollars from the federal Medicaid matching funds, providing an even more cost-effective way to serve people with neurobehavioral issues appropriately. This will reduce wasteful spending for the state as well as the number of people in our correctional and mental health systems.

# Conclusions, Recommendations, and Next Steps

## *Developing a Model of Care*

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### Conclusion

What Georgia needs most to improve care for its citizens with neurobehavioral issues is a coordinated system of care and support. A coordinated system of care is a cross-system, coordinated network of effective services and supports organized for the purpose of addressing the complex and changing needs of individuals with traumatic brain injury of all ages and their families, caretakers or circles of support. The Commission strongly recommends the development of a coordinated system of care for Georgians with significant behavioral issues resulting from traumatic brain injury. Such a coordinated system would significantly improve the quality of life for people with traumatic brain injury, reduce the use of state funds for inappropriate and ineffective services, and create a model of care for the rest of the country.

To accomplish this, the Commission recommends the following:

**Recommendation 1:** Create a legislative study committee to review this report and its recommendations, and to identify legislation, funding, responsible entities, and other infrastructure to create and support a coordinated system of care for Georgians with significant traumatic brain injuries.

The lack of a coordinated system for people with neurobehavioral issues is a serious public health issue and requires the involvement and attention of our state's leaders to develop a solution. While the Commission has conducted this study and issued its recommendations, ultimately, the thorough research of a legislative study committee is what's needed to establish an agenda for the state to improve the level of care and support for Georgians with neurobehavioral issues.

**Recommendation 2:** Develop a coordinated system of care that addresses the following four key components:

#### **I. Screening and identification**

- Expand capacity for behavior screening, assessment and evaluation for children and adults to identify people with significant behavioral issues resulting from brain injury. This can include:
  - Developing partnerships with other agencies;
  - Implementing the use of existing screening tools;
  - Providing training to professionals in a variety of agencies;
  - Developing methods for keeping current medical information in school records, and ensuring that medical history and current evaluations are considered in disciplinary proceedings for children and adolescents; and
  - Developing mobile resource and consultation teams at the state and local level.

#### **II. Training and awareness**

- Develop and provide training for direct support staff, providers, paraprofessionals, educators and other professionals to increase awareness and expertise in behavior associated with brain injury. This can include:
  - Collaborating with colleges, universities, and vocational schools to incorporate education and training on brain injury in their curricula;
  - Developing core competencies for direct support staff;
  - Developing training for professionals in a variety of disciplines; and
  - Developing and creating a mechanism to provide training for families and caregivers.
- Develop and maintain a centralized database of direct support staff, providers, paraprofessionals, educators and other professionals who have expertise in behavior associated with brain injury.

### **III. Rehabilitation**

- Expand funding sources and opportunities for post-acute rehabilitation, community and school re-entry services. This can include:
  - Developing sufficient funding to ensure that a person who sustains a TBI will receive adequate, specialized care and rehabilitation. This involves education of the Office of Medicaid and private insurance companies in order to expand the types of covered services for care and rehabilitation of TBI;
  - Creating a Home and Community Based waiver specific to TBI to ensure coverage of behavior interventions, home and residential based services, and crisis management services;
  - Working with the Office of Children's Medical Services to expand funding and services for the treatment of children with TBI;
  - Identifying opportunities for collaboration across agencies to address the needs of people with dual diagnoses; and
  - Developing opportunities to use telerehabilitation to increase access to specialized services.

### **IV. Long-term or life-long supports**

- Expand capacity for service coordination and case management services.
  - Providing sufficient funding for administrative or targeted case management services, including Medicaid and the waiver program, the Brain & Spinal Injury Trust Fund, and other state funding; and
  - Expanding service coordination and family support services for children with TBI using Georgia's Special Health Care Needs agency.
- Expand capacity for short-term, long-term and intermittent support such as professionally-designed behavioral supports, counseling, community-based and in-home care, personal care/support, and crisis management services. This can include:
  - Providing sufficient funding to pay for the supports necessary to support people with TBI in the community, including personal care, in-home care, and day programs;
  - Creating a Home and Community Based waiver specific to TBI to ensure coverage of services needed to support people with TBI in the community (see above);
  - Increasing revenue for the Trust Fund to increase funding for community supports for people with neurobehavioral issues;
  - Developing mobile resource and consultation teams at the state and local level (as discussed above); and
  - Developing other methods to provide crisis management services at the local level.
- Expand capacity for support services and respite options for caregivers. This can include:
  - Developing programs to increase support of caregivers of people with neurobehavioral issues. This includes collaborating with the Georgia Department of Human Resources, Division of Aging, to develop supports for aging caregivers.
- Develop capacity to provide for structured, community-based residential treatment and care for individuals who are a danger to themselves and others. This can include:
  - Developing specialized neurobehavioral programs that combine cognitive, behavioral and pharmacological treatments;
  - Developing options for crisis beds to allow someone to be removed from home or other setting in an emergency situation;
  - Developing residential options within a continuum of less-restrictive services; and
  - Expanding Medicaid and other state funding to provide sufficient coverage for residential neurobehavioral services, including an acceptable rate of pay for providers.

**Recommendation 3:** Provide oversight and the development of policies to support a coordinated system of care facilitated through the Brain & Spinal Injury Trust Fund Commission, which is the Lead Agency on Traumatic Brain & Spinal Injuries for the state of Georgia.

As the state's Lead Agency on Traumatic Brain & Spinal Injuries, the Commission is in the position of assisting with the development of a coordinated system of care for people with neurobehavioral issues in Georgia. The Commission's Advisory Committee is made up of representatives of key state agencies, people with TBI and their caregivers, service providers, advocates, and other stakeholders. Thus, many of the partners who would be involved in creating a coordinated system are already present at the Commission's table.

While the Commission is not proposing to develop and offer the range of services and funding that are needed to support people with TBI in the community, in its role as Lead Agency it is recommending that it oversee the development of such a system, working with the community of stakeholders to develop the appropriate services and funding.

## **In Summary**

**M**ost states that provide an array of services and supports for people with neurobehavioral issues have used a combination of funding and collaboration among state and private agencies. The Brain and Spinal Injury Trust Fund Commission can serve as a catalyst for that type of cooperation in order to develop a system that is responsive to the needs of individuals and their families. Developing a coordinated system of care for people with brain injury may require a redirection of existing funds (that are currently used to support people in inappropriate placements), new funding, changes in the state Medicaid program, and/or state legislation. This will require careful planning and work among all stakeholders.

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## Contributors

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### **LuRae Ahrendt RN, BSN, CRRN, CCM**

Ahrendt Rehabilitation, Inc.  
Co-chair, Brain Injury Association of Georgia  
Advisory Board  
Member, Children & Youth Subcommittee

### **Tom Connelly**

Advocate  
Rehabilitation Employment Specialist,  
Vocational Rehabilitation  
Member, Traumatic Injury Advisory Committee  
Member, Neurobehavioral Health Subcommittee  
Member, Brain Injury Task Force

### **Leanne Dennis, CTRS CCM**

Program Director, Shepherd Pathways  
Member, Neurobehavioral Health Subcommittee  
Member, Brain Injury Task Force

### **Catherine L. Frasier**

Advocate  
Board Member, Brain Injury Association of  
Georgia  
Member, Children & Youth Subcommittee  
Member, Brain Injury Task Force

### **Mimi Gold, M. Ed.**

Coordinator of Rehabilitation Teachers,  
Children's Healthcare of Atlanta  
Member, Traumatic Injury Advisory Committee  
Chair, Children & Youth Subcommittee

### **Bobby Goldberg**

Public Policy Consultant  
Ahead of the Curve, Inc.

### **Julie Haarbauer-Krupa, M.A., C.C.C.**

Research Scientist, Children's Healthcare of  
Atlanta  
Member, Children & Youth Subcommittee

### **Vickie S. Hodge**

Executive Director, Jimmy Simpson Foundation  
Vice President and Treasurer, Brain Injury  
Association of Georgia  
Member, Neurobehavioral Health Subcommittee  
Member, Brain Injury Task Force

### **Laura Bennett Howell, MS, LAPC**

Advocate  
Member, Neurobehavioral Health Subcommittee  
Member, Brain Injury Task Force

### **Cindi Johnson**

Executive Director, Side-by-Side Brain Injury  
Clubhouse  
Member, Neurobehavioral Health Subcommittee  
Member, Brain Injury Task Force

### **Susan Johnson, MA CCC CCM**

Director, Brain Injury Services, Shepherd Center  
Vice Chair, Brain & Spinal Injury Trust Fund  
Commission  
Chair, Traumatic Injury Advisory Committee  
Member, Brain Injury Task Force

### **Bridget Kelly, M.S.W.**

Director, Referral Relations, Restore  
Neurobehavioral Center  
Member, Neurobehavioral Health Subcommittee  
Member, Brain Injury Task Force

### **Stephanie P. Lotti**

Director of Data & Public Policy, Brain & Spinal  
Injury Trust Fund Commission

### **Marty McMorrow, MS**

Director of National Business Development  
The MENTOR Network

### **Suzan Patillo**

Lead Teacher, Visual Impairment & Traumatic  
Brain Injury Programs  
Gwinnett County Public Schools  
Member, Traumatic Injury Advisory Committee  
Member, Children & Youth Subcommittee

### **Bob Raubach**

Attorney, Georgia Advocacy Office  
Member, Neurobehavioral Health Subcommittee  
Member, Brain Injury Task Force

### **Cindy Minnix Saylor**

Advocate  
Program Coordinator, Partnerships for Success  
Member, Traumatic Injury Advisory Committee  
Chair, Neurobehavioral Health Subcommittee  
Chair, Brain Injury Task Force

### **Zelphine Smith-Dixon, Ed. D.**

Education Program Specialist, Division for  
Special Education Supports  
Georgia Department of Education  
Member, Brain & Spinal Injury Trust Fund  
Commission  
Member, Children & Youth Subcommittee

### **Craig Young**

Executive Director, Brain & Spinal Injury Trust  
Fund Commission



## Writers

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**Susan L. Vaughn**

Director of Public Policy, National Association of State Head Injury Administrators  
S.L. Vaughn & Associates, LLC

**Kristen E. Vincent**

Consultant, Brain & Spinal Injury Trust Fund Commission

## Appendix A

### *History of Efforts to Develop Services for People with Brain Injury*

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The state of Georgia is not alone in facing challenges to address the needs of people with brain injuries. For the past three decades the nation as a whole has struggled with the need to develop services, funding, and legislation to support the particular needs of people with brain injury, largely due to advances in medical care that have resulted in more people surviving these injuries and returning to the community for long-term support.

In Georgia, efforts to address the needs of people with brain injury began in 1983 when the Brain Injury Association of Georgia was first established. However, in the past decade the state has experienced a significant increase in efforts to support this population with the passage of the federal Traumatic Brain Injury (TBI) Act and its subsequent funding to states to develop a system of support for people with TBI, and with the establishment of the Brain and Spinal Injury Trust Fund. These two initiatives together provided an opportunity for people with brain injury, caregivers, experts, and advocates to come together to identify ways to enhance support for people with brain injury. This has culminated in the Commission becoming the Lead Agency on Traumatic Brain Injury for the state of Georgia, serving as a forum for stakeholders to develop public policy recommendations to enhance the lives of Georgians with brain injury.

#### **State and National Initiatives:**

- 1980 Brain Injury Association of America (BIAA) is established.
- 1983 Brain Injury Association of Georgia is established to develop support groups, advocacy, education and training for Georgians with brain injury.
- 1984 The federal Comprehensive Act for Families and Caregiver of Brain Injury Adults is enacted.
- 1985 The states of Wisconsin, Massachusetts, Missouri, and Pennsylvania appropriate state funds for people with Traumatic Brain Injury (TBI) and create advisory councils.
- 1987 U.S. Department of Education, National Institute of Disability and Rehabilitation Research (NIDDR) funds the first 5 TBI Model Systems of Care (there are now 14 TBI Model Systems of Care in the U.S.).
- 1988 U.S. Department of Health and Human Services, National Institute of Neurological Disorders and Stroke convenes a federal interagency Head Injury Task Force.
- 1989 Centers for Disease Control and Prevention (CDC) begin promoting the development of a multi-state TBI Surveillance System to track the incidence of TBI across the country.
- 1990 President George H. Bush declares the 1990's "The Decade of the Brain."
- 1990 Traumatic brain injury (TBI) is included as a diagnostic category of the federal Individuals with Disabilities Act.
- 1990 National Association of State Head Injury Administrators (NASHIA) is formed to provide support to state governments in the development of national- and state-level services and funding for people with TBI.

- 1991 Legislation passes that determines workers' compensation criteria for TBI eligibility.
- 1992 U.S. Department of Defense (DOD) establishes the Defense and Veterans Head Injury Center (now called the Defense and Veterans Brain Injury Center), a unique partnership between the DOD, the Department of Veterans' Affairs (VA) and a private provider of neurobehavioral services. The purpose of the Center is to prevent, treat, and provide education on brain injury for U.S. military personnel.
- 1994 Georgia Department of Human Resources (DHR) mandates designated Vocational Rehabilitation (VR) counselors for people with TBI and implements the VR Head Injury Program.
- 1996 Federal TBI Act (PL 104-166) is passed to expand studies and establish innovative programs with respect to TBI. The legislation authorizes the U.S. Department of Health and Human Resources and Services Administration (HRSA) to grant funds to states on a competitive basis to build infrastructure capacity, develop and evaluate service integration models, establish policy, and secure financial support to bring about lasting systems change for people with TBI.
- 1997 Georgia's State Health Planning Agency (SHPA) receives a 1-year HRSA Planning Grant and becomes the Lead Agency on Traumatic Brain Injury for the state of Georgia. The purpose of the grant is to develop a comprehensive analysis of the needs of Georgians with TBI and recommend actions to address those needs. As a result of the grant, SHPA:
1. appointed and developed a TBI advisory board;
  2. completed a statewide needs/resource assessment;
  3. developed a statewide action plan; and
  4. made recommendations to designate state agency and staff positions specific to TBI.
- 1998 Legislation is passed and a constitutional amendment is adopted to create the Brain and Spinal Injury Trust Fund using funds collected from a surcharge on all DUI fines to assist with the costs of care and rehabilitation for Georgians with TBI and spinal cord injury (SCI).
- 1998 SHPA is awarded a 3-year Implementation Grant from HRSA. The purpose is to increase interagency collaboration and linkages to improve access to individual and family services, with emphasis on children and minorities with TBI. As a result of the grant, SHPA:
1. Sponsored a TBI coalition building summit;
  2. Published a brochure on TBI in partnership with the Centers for Disease Control and Prevention;
  3. Collaborated with the Brain Injury Association of Georgia (BIAG) to expand the Association's help line and website;
  4. Funded 2 multicultural support groups for people with TBI;
  5. Provided computer support to the state's Central Registry;
  6. Collaborated with BIAG to provide training to emergency room personnel on TBI;
  7. Held quarterly meetings of the TBI steering committee (formerly the TBI advisory board); and
  8. Printed and distribute central registry annual report
- 1999 Governor appoints the first members of the Brain and Spinal Injury Trust Fund Commission ("Commission") to oversee distribution of the Trust Fund;
- 2001 Georgia Department of Community Health (DCH) takes over the role of Lead Agency on Traumatic Brain Injury from SHPA;
- 2002 Commission awards the first Trust Fund dollars to people with TBI and SCI;
- 2003 Commission takes over role of Lead Agency on Traumatic Brain Injury from DCH and expands focus to include SCI;

- 2004 Commission re-establishes the former TBI Steering Committee, renaming it the Traumatic Injury Advisory Committee;
- 2004 By agreement with the Georgia Department of Labor, the Commission takes over administration of the state's Central Registry for Traumatic Brain and Spinal Injuries, which gathers incidence data and provides critical resource information to people soon after their injuries.
- 2004 Commission receives a HRSA Post-Demonstration Grant to assist with implementing new procedures to improve data accuracy and collection for the Central Registry for Traumatic Brain and Spinal Injuries.
- 2006 Commission establishes the Neurobehavioral Health Subcommittee to bring stakeholders together to identify ways to improve the state system of services and funding for Georgians with neurobehavioral issues.
- 2006 Commission establishes the Children & Youth Subcommittee to bring stakeholders together to identify the needs of children with TBI and ways to improve the state system of services and funding for them.
- 2007 ABC News Anchor Bob Woodward hosts a prime-time television special on his brain injury and the needs of people, particularly soldiers, with brain injury. This leads to a partnership with the BIAA to promote services and funding for people with TBI.
- 2007 Heroes at Home Act of 2007, a series of initiatives to improve services and support for soldiers with brain injury and their families, is introduced to Congress.
- 2007 Commission renames the Neurobehavioral Health Subcommittee, designating it as the Brain Injury Task Force with the goal of implementing the recommendations of the Subcommittee as formed in its white paper on neurobehavioral issues. The Task Force is also broadened to address the needs of people with all types of brain injury, both acquired and traumatic, given the similarity in symptoms and service needs.

## Appendix B

### Matrix of Continuum of Care for People with Neurobehavioral Issues

The two matrices below illustrate the difference between the current system of services and a coordinated system of care for people with neurobehavioral issues.

#### Current Service System *(existing services, including both inappropriate and appropriate supports)*

	Age	Intensity of Support											
		Natural Supports*			Contained Community Supports**					Secured Unit or Institutionalization†			
Age-Appropriate for School Services	0 to 2	Family	School	Home & Community Based Services	Rehabilitation (Outpatient)	Respite	Rehabilitation (Inpatient and Outpatient)	Day Program	Sheltered Workshop	Foster Care (Including Therapeutic)	Group Home	Hosted Home	Respite
	3 to 5												
	6 to 13												
	14 to 17												
	18 to 21												
Adulthood	22 to 50	Family	School	Home & Community Based Services	Rehabilitation (Outpatient)	Respite	Rehabilitation (Inpatient and Outpatient)	Day Program	Sheltered Workshop	Foster Care (Including Therapeutic)	Group Home	Hosted Home	Respite
	51 to 64												
	65 thru end of life												

#### Coordinated System of Care *(appropriate supports in the community or least-restrictive setting)*

		Intensity of Support													
		Age	Natural Supports*				Contained Community Supports**				Structured, Community-Based Residential Care†				
Age-Appropriate for School Services	0 to 2	Family	School	Home & Community Based Services	Rehabilitation (Outpatient)	Respite	Rehabilitation (Inpatient and Outpatient)	Day Program	Foster Care (Including Therapeutic)	Group Home	Hosted Home	Respite	Community-Based Neurobehavioral Program – Temporary Crisis Management	Community-Based Neurobehavioral Program – Long-term Residential Care	Community-Based Neurobehavioral Program – Respite
	3 to 5														
	6 to 13														
	14 to 17														
	18 to 21														
Adulthood	22 to 50														
	51 to 64														
	65 thru end of life														

**\*Natural supports** – people with neurobehavioral issues who can, with proper supports and rehabilitation, live in the community, often in their own home or the home of a loved one.

**\*\*Contained community supports** – people with neurobehavioral issues who can live in the community, but who need more structured supports and intensive rehabilitation, and who may need to live in a community-based residential program, such as a group home.

**†Secured unit / Institutionalization or Structured, Community-Based Residential Care** – people with neurobehavioral issues who are unable to live in the community, who need more intensive support and rehabilitation, and who can only live in a secure, structured environment because of the threat they pose to themselves or others. In the current system this includes people who are being housed in prisons, state hospitals and nursing homes because of the lack of appropriate services. In a coordinated system of care these same people would either have sufficient supports to be able to live in the community, or would be supported in a community-based residential program that is designed to meet the needs of people with severe neurobehavioral issues.



## Appendix C

### Glossary

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#### Acquired Brain Injury (ABI)

A brain injury that is not hereditary, present at birth, or of a degenerative nature. Causes can include traumatic brain injury (TBI) as well as: anoxic/hypoxic injury (e.g. heart attack, carbon monoxide poisoning), intracranial surgery, seizure disorders and toxic exposure (e.g. substance abuse, ingestion or inhalation of volatile agents).

#### Activities of Daily Living

The tasks of everyday life, including eating, dressing, getting into or out of a bed or chair, taking a bath or shower, and using the toilet. Instrumental activities of daily living are activities related to independent living and include preparing meals, managing money, shopping, doing housework, and using a telephone. Also called ADL.

#### Acute Care

The phase of managing health problems which is conducted in a hospital on patients needing medical attention.

#### Acute Rehabilitation Program

The early phase of rehabilitation which usually begins as soon as the patient is medically stable. The program is designed to be comprehensive and based in a medical facility with a typical length of stay of 1-3 months. Treatment is provided by an identifiable team in a designated unit.

#### Behavior

The total collection of actions and reactions exhibited by a person.

#### Cognition

The conscious process of knowing or being aware of thoughts or perceptions, including understanding and reasoning.

#### Cognitive Rehabilitation

Therapy programs which aid persons in the management of

specific problems in perception, memory, thinking and problem solving. Skills are practiced and strategies are taught to help improve function and/or compensate for remaining deficits. The interventions are based on an assessment and understanding of the person's brain-behavior deficits and services are provided by qualified practitioners.

#### Frontal Lobe

Front part of the brain; involved in planning, organizing, problem solving, selective attention, personality and a variety of "higher cognitive functions."

#### Impulse Control

Refers to the individual's ability to withhold inappropriate verbal or motor responses while completing a task. Persons who act or speak without first considering the consequences are viewed as having poor impulse control.

#### Neurobehavior

An individual's ability to process thoughts or to think, behave socially, communicate, and control emotions. The term *neurobehavioral* is frequently used to describe the significant behavioral problems that often result from an injury to the brain, such as a traumatic brain injury. These cognitive and behavioral problems may relate to: concentration, memory and attention, impulsivity, aggression, irritability, depression, moodiness, and changes in personality.

#### Neurologist

A physician who specializes in the nervous system and its disorders.

#### Neuropsychologist

A psychologist who specializes in evaluating (by tests) brain/behavior relationships, planning training programs to help the survivor of brain injury return to normal functioning and recommending

alternative cognitive and behavioral strategies to minimize the effects of brain injury. Often works closely with schools and employers as well as with family members of the injured person.

#### Physiatrist

A physician who specializes in physical medicine and rehabilitation. Some physiatrists are experts in neurologic rehabilitation, trained to diagnose and treat disabling conditions from brain injury. The physiatrist examines the patient to assure that medical issues are addressed and provides appropriate medical information to the patient, family members and members of the treatment team. The physiatrist follows the patient closely throughout treatment and oversees the patient's rehabilitation program.

#### Rehabilitation

Comprehensive program to reduce/overcome deficits following injury or illness, and to assist the individual to attain the optimal level of mental and physical ability.

#### Traumatic Brain Injury (TBI)

A brain injury caused by a jolt, blow or penetrating injury to the brain. Georgia defines traumatic brain injury as "an injury to the brain, not of a degenerative or congenital nature, but arising from blunt or penetrating trauma from acceleration-deceleration forces, that is associated with any of these symptoms or signs attributed to the injury:

- decreased level of consciousness
- amnesia
- other neurological or neuropsychological abnormalities
- skull fracture or
- diagnosed intracranial lesions.

These impairments may be either temporary or permanent and can result in a partial or total functional disability."

# Facts about Traumatic Brain Injury

## What is a traumatic brain injury?

A traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Not all blows or jolts to the head result in a TBI. The severity of such an injury may range from "mild," i.e., a brief change in mental status or consciousness to "severe," i.e., an extended period of unconsciousness or amnesia after the injury. A TBI can result in short or long-term problems with independent function.

## How many people have TBI?

Of the 1.4 million who sustain a TBI each year in the United States:

- ♦ 50,000 die;
- ♦ 235,000 are hospitalized; and
- ♦ 1.1 million are treated and released from an emergency department.<sup>1</sup>

The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.

## What causes TBI?

The leading causes of TBI are:

- ♦ Falls (28%);
- ♦ Motor vehicle-traffic crashes (20%);
- ♦ Struck by/against events (19%); and
- ♦ Assaults (11%).<sup>1</sup>

Blasts are a leading cause of TBI for active duty military personnel in war zones.<sup>2</sup>

## Who is at highest risk for TBI?

- ♦ Males are about 1.5 times as likely as females to sustain a TBI.<sup>1</sup>
- ♦ The two age groups at highest risk for TBI are 0 to 4 year olds and 15 to 19 year olds.<sup>1</sup>
- ♦ Certain military duties (e.g., paratrooper) increase the risk of sustaining a TBI.<sup>3</sup>
- ♦ African Americans have the highest death rate from TBI.<sup>1</sup>

## What are the costs of TBI?

Direct medical costs and indirect costs such as lost productivity of TBI totaled an estimated \$60 billion in the United States in 2000.<sup>4</sup>

## What are the long-term consequences of TBI?

The Centers for Disease Control and Prevention estimates that at least 5.3 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of a TBI.<sup>5</sup>

According to one study, about 40% of those hospitalized with a TBI had at least one unmet need for services one year after their injury. The most frequent unmet needs were:

- ♦ Improving memory and problem solving;
- ♦ Managing stress and emotional upsets;
- ♦ Controlling one's temper; and
- ♦ Improving one's job skills.<sup>6</sup>

TBI can cause a wide range of functional changes affecting thinking, language, learning, emotions, behavior, and/or sensation. It can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age.<sup>7,8</sup>



## Collaborating Organizations

### **Brain Injury Association of America**

[www.biausa.org](http://www.biausa.org)  
800-444-6443

### **Centers for Disease Control and Prevention**

[www.cdc.gov](http://www.cdc.gov)  
800-311-3435

### **Defense and Veterans Brain Injury Center**

[www.dvbic.org](http://www.dvbic.org)  
800-870-9244

### **Health Resources and Services Administration**

[www.hrsa.gov](http://www.hrsa.gov)  
301-443-3376

### **National Association of State Head Injury Administrators**

[www.nashia.org](http://www.nashia.org)  
301-656-3500

### **National Brain Injury Research Treatment and Training Foundation**

[www.nbirtt.org](http://www.nbirtt.org)  
434-220-4824

### **National Center for Medical Rehabilitation Research, NICHD, NIH**

[www.nichd.nih.gov/about/ncmrr](http://www.nichd.nih.gov/about/ncmrr)  
800-370-2943

### **National Institute on Disability and Rehabilitation Research**

[www.ed.gov/about/offices/list/osers/nidrr](http://www.ed.gov/about/offices/list/osers/nidrr)  
202-245-7640

### **National Institute of Neurological Disorders and Stroke, NIH**

[www.ninds.nih.gov](http://www.ninds.nih.gov)  
800-352-9424

### **North American Brain Injury Society**

[www.nabis.org](http://www.nabis.org)  
703-960-6500

### **Social Security Administration**

[www.ssa.gov](http://www.ssa.gov)  
800-772-1213

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# Traumatic Brain Injury:

## A Guide for Criminal Justice Professionals

Many prison and jail inmates are living with traumatic brain injury (TBI)-related problems that complicate their management and treatment while incarcerated. Because most inmates will be released, these problems also pose challenges when they return to the community. The Centers for Disease Control and Prevention (CDC) recognizes TBI in prisons and jails as an important public health problem.

### What is Traumatic Brain Injury?

- A traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain.<sup>1</sup>
- Not all blows or jolts to the head result in a TBI. The severity of such an injury may range from “mild,” with a brief change in mental status or consciousness, to “severe,” with an extended period of unconsciousness or amnesia after the injury.<sup>1</sup>
- A study of young adults found that those with a TBI were at risk for sustaining another,<sup>2,3</sup> and that a history of multiple TBIs is associated with slower recovery.<sup>4</sup>

### How many people have TBI?

- Each year, on average 1.4 million people in the United States sustain a TBI. Of this number, 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from an emergency department.<sup>5</sup>
- At least 5.3 million Americans are living with TBI-related disabilities.<sup>6</sup>
- The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.<sup>7</sup>

### What are the causes of TBI?

- The leading causes of TBI are falls, motor vehicle-traffic crashes, struck by or against events, and assaults.<sup>5</sup>
- Blasts are the leading cause of TBI among active duty military personnel in war zones.<sup>8</sup>

### What are the long-term consequences of TBI?

- A person with a TBI can experience short- or long-term problems, requiring help in performing activities of daily living.<sup>1,6</sup>
- A TBI can cause a wide range of problems in thinking, sensation, learning, language, behavior, and/or emotions.<sup>9-11</sup>
- Persons with TBI may experience mental health problems such as severe depression,<sup>12</sup> anxiety,<sup>13</sup> difficulty controlling anger<sup>14</sup> and alcohol or substance abuse.<sup>15,16</sup>





- TBI can also cause epilepsy and increase the risk for both Alzheimer's and Parkinson's diseases and other brain disorders associated with increasing age.<sup>9</sup>

- Among male inmates, a history of TBI is strongly associated with perpetration of domestic violence and other kinds of violence during their lifetimes.<sup>32</sup>

## What is known about the extent of TBI and related problems within the criminal justice system?

### General:

- According to jail and prison studies, 25-87% of inmates report having experienced a head injury or TBI<sup>17-19</sup> as compared to 8.5% in a general population reporting a history of TBI.<sup>20</sup>
- Inmates who reported head injuries are more likely to have disciplinary problems during incarceration.<sup>21</sup>
- Inmates with head injuries may have seizures<sup>19</sup> or mental health problems such as anxiety<sup>22</sup> or suicidal thoughts and/or attempts.<sup>22,23</sup>
- Studies of inmates' self-reported health indicated that inmates with one or more head injuries have significantly higher levels of alcohol and/or drug use during the year preceding their current incarceration.<sup>22</sup>
- The U.S. Department of Justice has reported that 52% of female and 41% of male offenders were under the influence of drugs, alcohol, or both at the time of their arrest,<sup>24</sup> and that 64% of male arrestees tested positive for at least one of five illicit drugs (cocaine, opioids, marijuana, methamphetamines, or PCP).<sup>25</sup>
- Although more than half of prison inmates have a lifetime history of drug use disorders,<sup>26</sup> fewer than 15% receive substance abuse treatment services while in prison.<sup>27</sup>

### Women and Families:

- Female inmates who are convicted of a violent crime, are more likely to have sustained a pre-crime TBI and/or some other form of physical abuse.<sup>28</sup>
- Children and teenagers who have been convicted of a crime are more likely to have sustained a pre-crime TBI<sup>29</sup> and/or some other form of physical abuse.<sup>29-31</sup>

### Corrections and Law Enforcement Officers:

- Corrections personnel and law enforcement officers are at risk for head injury or fatal head trauma.<sup>33,34</sup>
- Interactions with suspects prior to arrest and with inmates during their incarceration are considered high risk situations for injury or death due to head trauma.<sup>35</sup>

## How might inmates with TBI and others be affected by TBI-related problems?

Within the correctional setting, TBI can contribute to situations that lead to disciplinary action. Here are some common TBI problems and strategies for management:

- Attention deficits may make it difficult for the inmate with TBI to focus on a required task or respond to directions given by a corrections officer. Either situation may be misinterpreted, thus leading to an impression of deliberate defiance on the part of the inmate.<sup>17,36</sup>
  - Management strategies:
    - Ask the inmate to repeat what you have said to confirm that he or she has heard and understood your directions
    - Encourage the inmate to write down steps for the task
    - Allow extra time for the task to be done
    - Clear or reduce environmental distractions
- Memory deficits can make it difficult to understand or remember rules or directions, which may lead to disciplinary actions by jail or prison staff.<sup>21</sup>
  - Management strategies:
    - Explain rules or directions slowly, step-by-step

- Ask the inmate to repeat the steps and encourage him or her to write down the information
  - Provide examples and ask the inmate to provide his or her own
  - Teach the inmate to ask questions when he or she doesn't understand
- Slowed verbal and physical responses may be interpreted by corrections officers as uncooperative behavior.<sup>36,37</sup>
  - Management strategies:
    - Give directions, or ask questions, slowly; repeat if necessary
    - Allow the inmate additional time to respond
- Irritability or anger may be difficult to control which can lead to an incident with another inmate or corrections officer. Such incidents can lead to further injury for the inmate with TBI and others.<sup>37,38</sup>
  - Management strategies:
    - Avoid arguing with the inmate
    - Try re-phrasing the problem, breaking it down into parts
    - Reinforce positive behaviors
- Uninhibited or impulsive behavior, including unacceptable sexual behavior, may provoke other inmates or result in disciplinary action by jail or prison staff.<sup>36,39</sup>
  - Management strategies:
    - Tell the inmate calmly that the behavior is unacceptable
    - Seek assistance from mental health professionals

## How can the problem of TBI in prisons and jails be addressed?

A recent report from the Commission on Safety and Abuse in America's Prisons recommended increased health screenings, evaluations, and treatment for inmates and development of partnerships with community health providers to assure continuity of care and case management for released inmates.<sup>40</sup>

In addition, TBI experts and some prison officials have suggested the following:

- Routinely screen jail and prison populations to identify a history of TBI.<sup>41,42</sup>
- Screen inmates with TBI for possible alcohol and/or substance abuse and provide treatment for these co-occurring conditions.<sup>25,43,44</sup>
- Conduct additional evaluations to identify specific TBI-related problems and determine how they should be managed.<sup>41</sup> Special attention should be given to impulsive behavior, including violence,<sup>39</sup> sexual activity,<sup>36</sup> and suicide risk if the inmate is depressed.<sup>45</sup>

## How should TBI-related problems be addressed after release from jails and prisons?

Lack of treatment and rehabilitation for inmates with mental health and substance abuse problems while incarcerated increases the probability that they will again abuse alcohol and/or drugs when released.<sup>25,44</sup> Persistent substance abuse can lead to homelessness,<sup>46</sup> return to illegal drug activities,<sup>47</sup> re-arrest,<sup>48</sup> and increased risk of death<sup>49</sup> after release. As a result, criminal justice professionals and TBI experts have suggested the following:

- Community re-entry staff should be trained to identify a history of TBI and have access to appropriate consultation with other professionals with expertise in TBI.<sup>29,41,42</sup>
- Transition services should be capable of accommodating the effects of an inmate's TBI upon their release and return to the community.<sup>29,41,42</sup>
- Released inmates with mental health and/or substance abuse problems should receive case management services and assistance with placement into community treatment programs.<sup>40,43,49</sup>

CDC supports new research to develop better methods for identifying inmates with a history of TBI and related problems and for determining how many are living with such injury.



## Further information is available from these websites:

### **Traumatic Brain Injury (TBI):**

CDC, National Center for Injury Prevention and Control  
[www.cdc.gov/ncipc/tbi/TBI.htm](http://www.cdc.gov/ncipc/tbi/TBI.htm)

This site provides information for professionals and the general public regarding TBI. Topics include prevention, causes, outcomes, and research. Data reports on TBI in the United States and many free publications and fact sheets can be downloaded. Materials are available in English and Spanish.

### **Health Issues in Correctional Settings:**

CDC, National Center for HIV, STD, and TB Prevention  
[www.cdc.gov/nchstp/od/cccwg/default.htm](http://www.cdc.gov/nchstp/od/cccwg/default.htm)

This site provides information for public health and criminal justice professionals about health topics with an emphasis on infectious diseases in the correctional setting. It also includes materials for the general public with links to related organizations.

### **Intimate Partner Violence (IPV):**

CDC, National Center for Injury Prevention and Control  
[www.cdc.gov/ncipc/factsheets/ipvfacts.htm](http://www.cdc.gov/ncipc/factsheets/ipvfacts.htm)

This site provides information for professionals and the general public regarding IPV. The site contains an overview and fact sheet about IPV, prevention strategies, links to other IPV organizations, and a list of current CDC publications.

### **Legal Issues of Persons with TBI within Correctional Settings:**

National Disability Rights Network  
[www.ndrn.org/aboutus/consumer.htm](http://www.ndrn.org/aboutus/consumer.htm)

This site provides information about the laws protecting the civil and human rights of people with disabilities including those with TBI. Inmates with disabilities or their families can receive help from the Network about inmates' legal rights, access to mental health services and/or medication, and restoration of benefits upon release.

### **Substance Abuse:**

Substance Abuse & Mental Health Services Administration  
[www.samhsa.gov](http://www.samhsa.gov)

This site provides information for professionals and the general public regarding treatment resources for persons with, or at risk for, mental health and/or substance abuse problems. It also has materials for specific populations and age groups and hotlines.

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# Traumatic Brain Injury in Prisons and Jails:

## An Unrecognized Problem

Many people in prisons and jails are living with traumatic brain injury (TBI)-related problems that complicate their management and treatment while they are incarcerated. Because most prisoners will be released, these problems will also pose challenges when they return to the community. The Centers for Disease Control and Prevention (CDC) recognizes TBI in prisons and jails as an important public health problem.

### What is known about TBI and related problems in prisons and jails?

#### General:

- More than two million people currently reside in U.S. prisons and jails.<sup>1</sup>
- According to jail and prison studies, 25-87% of inmates report having experienced a head injury or TBI<sup>2-4</sup> as compared to 8.5% in a general population reporting a history of TBI.<sup>5</sup>
- Prisoners who have had head injuries may also experience mental health problems such as severe depression and anxiety,<sup>3</sup> substance use disorders,<sup>6-8</sup> difficulty controlling anger,<sup>6</sup> or suicidal thoughts and/or attempts.<sup>6,9</sup>

#### Women:

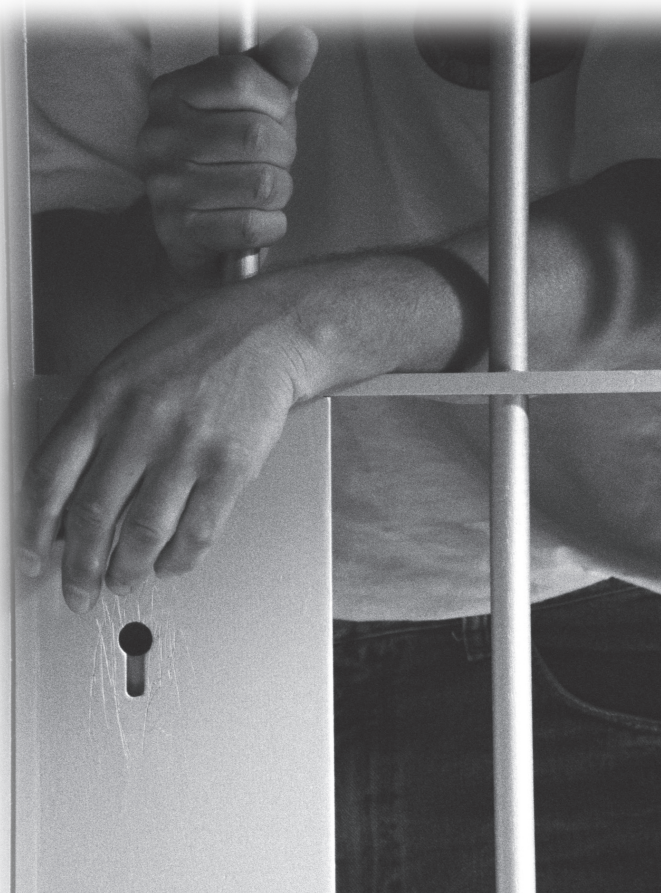
- Although women are outnumbered by men in U.S. prisons and jails, their numbers more than doubled from 1990 to 2000.<sup>1,10</sup> As of June 2005, more than 200,000 women were incarcerated.<sup>1</sup> Women now represent 7% of the total U.S. prison population and 12% of the total U.S. jail population.<sup>10</sup>
- Women inmates who are convicted of a violent crime are more likely

to have sustained a pre-crime TBI and/or some other form of physical abuse.<sup>11</sup>

- Women with substance use disorders have an increased risk for TBI compared with other women in the general U.S. population.<sup>12</sup>
- Preliminary results from one study suggest that TBI among women in prison is very common.<sup>13</sup>

#### Substance abuse, violence, and homelessness:

- Studies of prisoners' self-reported health indicate that those with one or more head injuries have significantly higher levels of alcohol and/or drug use during the year preceding their current incarceration.<sup>6</sup>
- The U.S. Department of Justice has reported that 52% of female offenders and 41% of male offenders are under the influence of drugs, alcohol, or both at the



time of their arrest,<sup>14</sup> and that 64% of male arrestees tested positive for at least one of five illicit drugs [cocaine, opioids, marijuana, methamphetamines, or PCP].<sup>15</sup>

- Among male prisoners, a history of TBI is strongly associated with perpetration of domestic and other kinds of violence.<sup>16</sup>
- Children and teenagers who have been convicted of a crime are more likely to have had a pre-crime TBI<sup>17,18</sup> and/or some other kind of physical abuse.<sup>17,19,20</sup>
- Homelessness has been found to be related to both head injury<sup>21</sup> and prior imprisonment.<sup>22</sup>

## How do TBI-related problems affect prisoners with TBI and others during their incarceration?

### A TBI may cause many different problems:

- Attention deficits may make it difficult for the prisoner with TBI to focus on a required task or respond to directions given by a correctional officer. Either situation may be misinterpreted, thus leading to an impression of deliberate defiance on the part of the prisoner.<sup>2,23</sup>
- Memory deficits can make it difficult to understand or remember rules or directions, which can lead to disciplinary actions by jail or prison staff.<sup>24</sup>
- Irritability or anger might be difficult to control and can lead to an incident with another prisoner or correctional officer and to further injury for the person and others.<sup>23,25</sup>
- Slowed verbal and physical responses may be interpreted by correctional officers as uncooperative behavior.<sup>23</sup>
- Uninhibited or impulsive behavior, including problems controlling anger<sup>6</sup> and unacceptable sexual behavior, may provoke other prisoners or result in disciplinary action by jail or prison staff.<sup>23,26</sup>

## What is needed to address the problem of TBI in jails and prisons?

A recent report from the Commission on Safety and Abuse in America's Prisons recommends increased health screenings, evaluations, and treatment for inmates.<sup>27</sup>

In addition, TBI experts and some prison officials have suggested:

- Routine screening of jail and prison inmates to identify a history of TBI.<sup>28,29</sup>
- Screening inmates with TBI for possible alcohol and/or substance abuse and appropriate treatment for these co-occurring conditions.<sup>15,30,31</sup>
- Additional evaluations to identify specific TBI-related problems and determine how they should be managed.<sup>28</sup> Special attention should be given to impulsive behavior, including violence,<sup>2,26</sup> sexual behavior<sup>23</sup> and suicide risk if the inmate is depressed.<sup>32</sup>

## What is needed to address TBI-related problems after release from jails and prisons?

Lack of treatment and rehabilitation for persons with mental health and substance abuse problems while incarcerated increases the probability that they will again abuse alcohol and/or drugs when released.<sup>15,31</sup> Persistent substance problems can lead to homelessness,<sup>33</sup> return to illegal drug activities,<sup>34,35</sup> re-arrest,<sup>36</sup> and increased risk of death<sup>37</sup> after release. As a result, criminal justice professionals and TBI experts have suggested the following:

- Community re-entry staff should be trained to identify a history of TBI and have access to appropriate consultation with other professionals with expertise in TBI.<sup>17,29,30</sup>
- Transition services for released persons returning to communities should accommodate the problems resulting from a TBI.<sup>17,28,29</sup>
- Released persons with mental health and/or substance abuse problems should receive case management services and assistance with placement into community treatment programs.<sup>27,30,37</sup>

CDC supports new research to develop better methods for identifying inmates with a history of TBI and related problems and for determining how many of them are living with such injury.



## Further information is available from these websites:

### **Traumatic Brain Injury (TBI):**

CDC, National Center for Injury Prevention and Control  
[www.cdc.gov/ncipc/tbi/TBI.htm](http://www.cdc.gov/ncipc/tbi/TBI.htm)

This site provides information for professionals and the general public regarding TBI. Topics include prevention, causes, outcomes, and research. Data reports regarding TBI in the United States and many free publications and fact sheets can be downloaded. Materials are available in English and Spanish.

### **Health Issues in Correctional Settings:**

CDC, National Center for HIV, STD, and TB Prevention  
[www.cdc.gov/nchstp/od/cccwg/default.htm](http://www.cdc.gov/nchstp/od/cccwg/default.htm)

This site provides information for public health and criminal justice professionals about health topics with an emphasis on infectious diseases in the correctional setting. It also has materials for the general public with links to related organizations.

### **Intimate Partner Violence (IPV):**

CDC, National Center for Injury Prevention and Control  
[www.cdc.gov/ncipc/factsheets/ipvfacts.htm](http://www.cdc.gov/ncipc/factsheets/ipvfacts.htm)

The site provides information for professionals and the general public regarding IPV. The site contains an overview and fact sheet about IPV, prevention strategies, links to other IPV prevention organizations, and a list of current CDC publications.

### **Legal Issues of Persons with TBI within Correctional Settings:**

National Disability Rights Network  
[www.ndrn.org/aboutus/consumer.htm](http://www.ndrn.org/aboutus/consumer.htm)

This site provides information about the laws protecting the civil and human rights of persons with disabilities, including TBI. Incarcerated persons with disabilities, or their families, can receive help from the Network regarding prisoners' legal rights, access to mental health services and/or medication, and restoration of benefits upon release.

### **Substance Abuse:**

Substance Abuse & Mental Health Services Administration  
[www.samhsa.gov](http://www.samhsa.gov)

This site provides information about treatment resources for persons with, or at risk for, mental and/or substance abuse problems. Also, the site provides information for professionals regarding alcohol and other drug-related disorders. The site has materials for specific populations and age groups and hotline numbers for support organizations.

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# Victimization of Persons with Traumatic Brain Injury or Other Disabilities:

## A Fact Sheet for Professionals

### What is victimization?

According to the U.S. Department of Justice (2004), victimization occurs when "...a person suffers direct or threatened physical, emotional, and/or financial harm." Victimization can include physical violence, sexual violence, psychological or emotional abuse, and neglect. The Centers for Disease Control and Prevention (CDC) acknowledges such victimization as a serious and preventable public health problem.

- **Physical violence** is "the intentional use of physical force with the potential for causing death, disability, injury, or harm." (Rosenberg and Mercy 1991; CDC 2006) It includes, but is not limited to, "scratching, pushing, shoving, throwing, grabbing, biting, choking, shaking, slapping, punching, burning, use of a weapon, and use of restraints or one's body, size, or strength against another person." (CDC 2006)
- **Emotional abuse** occurs when a person is "threatened, terrorized, or severely rejected, ignored, or verbally attacked." (Nosek et al. 2001) It includes, but is not limited to, "episodes of yelling, threats, or acts meant to humiliate or hurt feelings." (Curry et al. 2003)
- **Neglect** is a "situation in which the basic needs of a person (such as food, clothing, hygiene, protection, or medical care) are temporarily or permanently not met." (Verdugo and Bermejo 1997) It includes, but is not limited to, "preventing a person with disabilities from using a wheelchair, cane, respirator, or other assistive devices as well as failure to address basic needs for food, clothing, shelter, or hygiene." (McFarlane et al. 2001)
- **Sexual violence** is "the use of physical force to compel a person to engage in a sexual act against his or her will, whether or not the act is completed; an attempted or completed sex act involving a person who is unable to understand the nature or condition of the act, to decline participation, or to communicate unwillingness to engage in the sexual act; and abusive sexual contact." (CDC 2004)





## What is the extent of the problem?

Current knowledge about victimization of persons with disabilities is based on a small number of studies, and little is known about victimization of important groups such as persons with traumatic brain injury (TBI) (Marge 2003).

- Persons with disabilities are 4 to 10 times more likely to become a victim of violence, abuse, or neglect than persons without disabilities (Petersilia 2001).
- Children with disabilities are more than twice as likely to be physically or sexually abused as children without disabilities (Petersilia 2001; Sobsey and Mansell 1994).
- Similar proportions of women with and without disabilities report having experienced episodes of physical violence, sexual violence, or emotional abuse (Sobsey and Mansell 1994). Women with disabilities, however, report greater numbers of perpetrators and longer time periods of individual episodes than women without disabilities (Young et al. 1997).

## Where does victimization occur?

- Victimization can occur anywhere; however, it usually happens in isolated locations where a person with disabilities has little or no control of the environment (Sobsey and Mansell 1994), and the setting is away from the view of law enforcement (Verdugo and Mermejo 1997).
- Institutional settings are risk locations for persons with disabilities because multiple episodes of physical and sexual violence, emotional abuse, neglect, or violence may be committed against them by staff or other residents and yet go undetected or unreported (Sobsey and Mansell 1994; Brown and Turk 1994; Turk and Brown 1993).

## Who commits acts of victimization?

- More men than women, either as intimate partners or as health care workers (Brown and Turk 1994; Marley and Buila 2001), are reported to commit acts of physical violence, sexual violence, emotional abuse, or neglect against persons with disabilities.
- Family members have been reported to commit crimes of victimization while caring for a relative with disabilities (Milberger et al. 2003; Stromsness 1993).
- Personal home care attendants (Oktay and Tompkins 2004; Saxton et al. 2001) or health care workers at institutions (Brown and Turk 1994; Sequeira and Halstead 2001) have been reported to perpetrate emotional abuse and sexual violence against persons with disabilities.
- In institutional settings, persons with disabilities may commit acts of physical violence or sexual violence against other persons with disabilities (Sobsey and Doe 1991).

## What factors make a person with disabilities susceptible to victimization?

### Societal Factors:

- Misperceptions about disability include “having a disability protects a person from victimization”; the risks to a person with disabilities are thought to be less than the risks to a person who has none (Young et al. 1997).
- Unemployment or underemployment of persons with disabilities restricts their income and limits their choices for caregivers, leading to an increased risk of physical and sexual violence, emotional abuse, or neglect (Stromsness 1993).
- Lack of money often causes persons with disabilities to live in areas where crime rates are high and the potential for physical and sexual violence is greater than in wealthier neighborhoods (Curry et al. 2001).

## Community Factors:

- Community resources for victims of physical and sexual violence, emotional abuse, or neglect are usually designed to assist people without disabilities (Swedlund and Nosek 2000; Chang et al. 2003; Cramer et al. 2003). Organizations that provide such resources do not routinely collaborate with organizations that assist persons with disabilities (Curry et al. 2001; Swedlund and Nosek 2000; Chang et al. 2003).
- Frequently, health care (Swedlund and Nosek 2000; Chang et al. 2003; Cramer et al. 2003) and law enforcement (DOJ 1998) professionals are uninformed about victimization of persons with disabilities. Thus, they may not have the specialized knowledge or skills to identify and assist these individuals when victimized.
- TBI outcomes affect others' perceptions of a person's ability to honestly and accurately report an incident of victimization (DOJ 1998).
- Persons with TBI or other disabilities may experience physical and sexual violence, emotional abuse, or neglect by a caregiver in return for access to medication, adaptive equipment, or assistance with activities of daily life (Oktay and Tompkins 2004).

## What factors make a person with a traumatic brain injury, or TBI, susceptible to victimization?

### Relationship Factors:

- Persons living with a TBI often have difficulty with anger management, which may prompt others to use undue physical force or inappropriate medication (Kim 2002).
- Misperceptions about TBI and its effects may lead to treatment that is demeaning or abusive (Sequeira and Halsted 2001).
- A TBI can cause cognitive problems that reduce one's ability to perceive, remember, or understand risky situations that could lead to an incident of physical or sexual violence (Kim 2002; Levin 1999).
- Persons with a TBI may engage in at-risk drinking or drug use that place them in situations or relationships that lead to episodes of victimization (Kwasnica and Heinemann 1994; Li et al. 2000).
- In some persons, a TBI causes uninhibited behaviors that lead to risky sexual engagement, exposing them to HIV/AIDS or other sexually transmitted diseases (Jaffe et al. 2000; Kramer et al. 1993).

### Individual Factors:

## Information and Support

### Brain Injury Association of America

At the national and state level, the Association serves as a clearinghouse for community service information for persons with TBI, their families, and sponsors of educational programs.

800-444-6443

[www.biausa.org](http://www.biausa.org)

### Defense and Veterans Brain Injury Center

Serves active-duty military personnel and veterans who acquired TBI in the line of duty; provides medical care and educational programs for them and their dependents.

800-870-9244  
662-6345 (DSN)

[www.dvbic.org](http://www.dvbic.org)

### National Disability Rights Network

Voluntary association of protection and advocacy systems and client-assistance programs. Promotes rigorous enforcement of laws protecting the civil and human rights of persons with disabilities, including those with TBI.

202-408-9514  
202-408-9521  
(TTY)

[www.ndm.org](http://www.ndm.org)

### National Domestic Violence Hotline

Provides information and advice about domestic violence; makes referrals to local resources and shelters.

800-799-SAFE  
800-787-3224  
(TTY)

[www.ndvh.org](http://www.ndvh.org)



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